Facing Challenges on Campus

The Experiences of Postsecondary Students with Disabilities

by

Brian Barth

A Thesis submitted to the Faculty of Graduate Studies of

The University of Manitoba

in partial fulfilment of the requirements of the degree of

MASTER OF ARTS

November 2, 2005

Department of Anthropology

University of Manitoba

Winnipeg

THE UNIVERSITY OF MANITOBA

FACULTY OF GRADUATE STUDIES
*****
COPYRIGHT PERMISSION

Facing Challenges on Campus

The Experiences of Postsecondary Students with Disabilities

BY

Brian Barth

A Thesis/Practicum submitted to the Faculty of Graduate Studies of The University of

Manitoba in partial fulfillment of the requirement of the degree

Of

MASTER OF ARTS

Brian Barth © 2006

Abstract

My objective in this research thesis was to ethnographically document, analyze and contextualize the lived experiences of postsecondary students with disabilities. Specific focus in the documentation was placed on the relationship between the social experience of disability and the accessibility of postsecondary education. The case used to explore these questions was the University of Manitoba.

Fifteen students volunteered to share their experiences of disability in the context of their academic programs. Their experiences are informed by social relationships in a grand built environment of time, space and society. In this way, participant experiences place the definitions, meanings and interpretations of disability at the front of their explanations about lived experience of being disabled.

Through an analysis of extensive data, significant and overarching themes emerged. Students with disabilities express having to put in a great deal of work to overcome barriers to their education, and they express extreme gratefulness for the supports that are already available. Beyond this the participants have proven to be strong advocates for themselves and others in creating an accessible university experience. The participant experiences are a form of expertise which makes these people an invaluable resource in any creation of accessibility on a university campus.

Acknowledgments

There are many people who have helped to make my research a fruitful, engaging and enjoyable process. First, the participants deserve many thanks for taking time to be interviewed. All of these people were enrolled in academic programs at the time of my study, and, as a postsecondary student myself, I very much appreciate their flexibility and contribution. Secondly, the coordinator of Disability Services, Janalee Morris-Wales was always full of encouragement and input. Janalee and Dr. Lynn Smith (director of Student Affairs/Student Resource Services) agreed to distribute my request for participants to students registered at Disability Services. This was of great help in my recruitment process. Thirdly, I would like to thank my mentor, Alexander M. Ervin, for inspiring me to pursue applied anthropology in the first place. Finally, my thesis supervisor and committee members have been patient and full of constructive and consistent advice. My research was no doubt made rich and full by my committee's help, but it was also made challenging and full of satisfying learning experiences.

Table of Contents

Chapter One: Introduction

Postsecondary Students with Disabilities

University education has become more and more essential for employment in our so-called "knowledge-based" economy. The demand for a more thoroughly trained workforce has seen a rise in enrolment in postsecondary institutions.

It is widely established that people with disabilities have less success in finding employment than people who are not disabled (Statistics Canada 1993). In the past several decades, the deinstitutionalization of disabled people has interacted with movements for "disability rights" (among disabled and non-disabled persons alike) to create a population of citizens who are not only available to, but who are interested in pursuing postsecondary education as part of employment goals. Students with disabilities have been accommodated on university and college campuses in a variety of ways, and at the University of Manitoba since the early 1980's (Morris-Wales, personal communication 2003).

University education is difficult and challenging for most students. There are also several rewards and satisfying experiences that come as part of engagement in such an education. Students with disabilities no doubt face similar challenges and rewards. This research is an exploration of the university experiences specific to disabled students. By systematically documenting and analyzing some of these experiences, I wish to continue the addition of these people's voices to the knowledge base that informs policy design and service provision.

Research Questions

The objective of my research was to answer three questions:

1. What are the lived experiences of postsecondary students with disabilities at the University of Manitoba as described by these students?

2. How can these lived experiences inform the provision of supports and initiation of accessibility in postsecondary education?

3. How do the lived experiences of postsecondary students with disabilities contribute to understanding larger theories and concepts about disability in society?

I addressed these questions with the help of fifteen students who, at the time of the research were enrolled in university programs, and who identified themselves as disabled people, or persons with disabilities.

My Contextualizing Experiences

As all researchers, my past experiences with disabled people and postsecondary education create a context into which my enquiry fits. This context is not a problem for my research, but it bears mention nonetheless. I have worked several part-time jobs as an attendant care staff, and residential/recreation/vocational support worker. Through these various jobs, I have met people with disabilities who are young and old and who represent diverse personalities and diverse experiences of disability.

As a postsecondary student, I have attended three universities in Canada at the graduate and undergraduate levels. Like many students who have attended university, I have enrolled in courses across almost all disciplines.

My interest in a scholarly approach to disability came about for several reasons. First, I am interested in conducting research that can be applied directly with, and for, those people who participate. Second, the nature of acquired disability leaves me with the sense that "it could happen to anyone, even me". In other words, by contributing to the study of disability I am motivated to support those who are disabled, and at the same time I am motivated to create a "culture of support" for any who end up acquiring a disability.

My goal in the research and analysis that follows is not to sterilize my contextualizing experiences. Rather, I am informing you of this context in order for you to evaluate how I have augmented and expanded upon it through my enquiry. And indeed, this is the explicit and over-all goal of my scholarship.

Key Terms and Language

Throughout this thesis I will be using several key terms on a consistent basis. While these terms have multiple origins and uses, I will use them as follows unless I otherwise specify. *Disability* is the lived experience of being disadvantaged and/or dependent in society as a result of culturally constructed environments of time and space. As I use the term, disability does not require clinical diagnosis, but does require self-identification. *Impairment* is a characteristic of one's body or mind that may or may not interact with the culturally constructed environment to create a disabling experience for the

impaired person. Impairment can be clinically defined, but is not always medicalized. *Access* is the initial and/or continued ease of equal participation or engagement in one's society and culture. *Supports* are characteristic(s) of the culturally constructed environment of space and time that partially or wholly enable full participation by a person with a disability. A *barrier* is a feature of time or space (culturally constructed or not) that prevents access to full participation in society for a person with a disability.

The definitions of disability and impairment, as well as barriers and access are not without their problems. Scholars have produced analyses and typologies of some diverse uses and meanings of such terms (Altman 2004). At the same time, international organizations such as the World Health Organization (WHO) have built complicated and broad schemes for classifying disability in terms of clinical assessment and social context (World Health Organization 2004). It is beyond the scope of this research to engage fully with the debates and dialogue on how disability and its lexical ilk are defined by communities of clinicians, scholars, citizens and others.

That said, sensitivity to the existence of multiple definitions and discourses is important to the analysis of participants' personal experiences. In other words, participants sometimes adopt specific disability discourse(s) (such as the biomedical discourse) for pragmatic reasons and yet adopt other discourses (such as the disability rights discourse) when they are advocating for entitlement to supports.

A specific note on the nature of language is required at this point. Whether to say "**person with a disability**" or "**disabled person**" is an issue I have yet to resolve. Different scholars, organizations and individuals each have their own preferences and justifications for choosing either person-centered language or disability-centered language. Others would see the above as a simple false dichotomy used to refer to extreme diversity (Tichokosky 2001). Still other scholars have taken this polemic as a site of investigation in itself (Tichkosky 2001; Finlon-Dajani 2001). In my encounters with disabled people and service organizations, the experience of disability is as varied and heterogeneous as are the understandings of what this experience means. In order to do justice to this diversity, and in order to skirt an issue that is irresolvable in the scope of this research, I will refer interchangeably to this population as both disabled people and people with disabilities.

Postsecondary Education and Disability in Canada

Disability and postsecondary education are of course connected in the lived experiences of students with disabilities. There are deeper connections evident when one stands back and observes larger social structures. There is little doubt that the capitalist-industrial mode of production (among other systems) has not favored or suitably accommodated people with disabilities (Tregaskis 2002; Drake 2001; Barnes 1996; Oliver 1990; Finklestein 1980). Drake provides a cogent analysis of the relationship between disabled people, welfare states, and the capitalist mode of production (Drake 2001). Because states need to keep people employed in order to maintain healthy industry and commerce, social safety-net policy is often built to provide discouragingly minimal means-tested support to disabled people (Drake 2001). Moreover says Drake, in the administration of services for disabled persons, states have condoned and licensed clinicians, thereby fostering the existence of the medical model (a model that locates disability in the individual, and leaves the social environment out of the equation) (Drake 2001).

Human Resources and Development Canada (HRDC) asserts a well established fact: university graduates earn more than graduates of college programs and trade/vocational programs (Human Resources Development Canada 2003). While people with disabilities exhibit higher rates of unemployment than their non-disabled counterparts in Canada, it is no surprise

that research demonstrates that for people with disabilities, the higher the level of education, the lower the unemployment rate (Fawcett 1996).

In addition to higher education being a benefit to disabled people, it may also be a necessity. The emergence of the so called "knowledge-based-economy" during the past thirty years in Canada creates an employment environment that demands workers who have more intensive educations. Beckstead and Vinodrai concluded that this trend has emerged in Canada in a geographically uniform way, and across all industries (Beckstead and Vinodrai 2003). More interesting still is the finding that "Only 44% of professional occupations had a postsecondary degree in 1971 but 68% had such a degree in 1996" (Beckstead and Vinodrai 2003:5).

Because postsecondary education produces employees with more skills (or at least more credentials), university graduates are more competitively employable in a knowledge-based-economy. The emergence of the knowledge-based-economy in Canada has seen new jobs created in sectors other than labor and manufacturing (recall these sectors have traditionally excluded people with disabilities). The employment prospects of persons with disabilities (and indeed Canadians in general) are perhaps more dependent than ever on the attainment of higher education.

In terms of policies governing service provision for disabled people, the current state of affairs in Canada can be thought of in two ways. First, the population of Canadians with disabilities itself displays important contextualizing

features. Secondly, Canadian social policy itself represents a "built environment"

encountered by Canadians with disabilities.

Several features of the population of Canadians with disabilities need

highlighting. According to *A Profile of Disability in Canada* (the PDC) one in eight

(twelve and a half percent) Canadians live with at least one disability (Statistics

Canada; Housing 2002). The PDC explains that these disabilities cover a wide

range of clinically defined experiences; visual and auditory impairments, physical

and cognitive impairments, psychiatric and learning impairments, and several

others (Statistics Canada; Housing 2002).

Of interest in the PDC is the fact that more disabilities are present in

persons between ages 25 and 65 than are present in any other age group

(Statistics Canada: Housing 2002). This is because many disabilities require

chronological manifestation in order to be identified, and because, as people age,

they acquire non-congenital impairments (resulting from injury and disease etc.)

(Statistics Canada; Housing 2002). Also of note is the higher rate of women

than men who exhibit disabilities in Canada (Statistics Canada; Housing 2002).

Perhaps the most interesting of all features of this population (at least regarding

this research) is their economic status. Forty-eight percent—almost half—of

Canadians with disabilities have incomes less than $20 000 CDN per year

(Statistics Canada; Housing 2002).

Social policy regarding disabled persons in Canada is broad and sets out

many requirements of public and private agencies. Several programs are

available specifically for Canadians with disabilities regarding income, education

and housing. Still other government agencies offer disability-specific programs in addition to their programs for non-disabled Canadians. *Defining Disability: A complex issue* (DD) is a review of laws and programs that are relevant and available to disabled persons in Canada (Human Resources Development Canada 2003). In relation to accessing postsecondary education, the DD document (Human Resources Development Canada 2003) lists a variety of programs. Although many, these supports may remain inaccessible because of various and inconsistent application requirements (Ficten 1995).

Statistics Canada reports that for the year 2001, 7820 Manitobans with disabilities had attained a university education while 105 030 of Manitobans without disabilities had attained such an education (Statistics Canada 1993). The University of Manitoba is a degree-granting postsecondary institution with programs at the undergraduate and graduate levels in a large variety of disciplines. Attendance for the year 2002 at the University of Manitoba consisted of 21 724 undergraduate and 2852 graduate students (University of Manitoba Office of Institutional Analysis 2004). In the academic year of 2003-2004, the University Of Manitoba Office Of Disability Services provided accommodations for over 600 full and part time students; the year before, only half as many students were registered at the office (Janalee Morris-Wales, personal communication 2004).

Without doubt, disabled Canadians are attending and completing university programs (HRDC 2001; Statistics Canada 2001, 2003). In terms of employment, it is apparent that university education can only work to the

advantage of Canadians with disabilities. This is partly because university

education is beneficial in general and leads to higher rates of employability

(Statistics Canada 2003).

Enrolment at the University of Manitoba has been gradually increasing

over at least the past five or so years (University of Manitoba Office of

Institutional Analysis 2004). As general enrolment rises, it is reasonable to

expect that the enrolment of students with disabilities will keep pace. While

many of these students are using formal services at the University of Manitoba,

there may yet be more students with disabilities who are enrolled but do not use

formal services. In other words, there is a population of at least 600 or so

students who experience disability in the context of their postsecondary

education.

The significance and value of this research centers around what the

student experiences can tell us about how easy or difficult it is for disabled

people to access a university education. Moreover, this research is significant

because it can tell us about how the disability-education-employment connection

is understood by disabled students themselves.

Theoretical Frameworks

The Social Model of Disability

The first of two key theoretical foundations to this research, Social Model Theory

(SMT) has been used by scholars to approach disability for at least twenty years

(Tregaskis 2002; Thomas and Corker 2002). The Social Model of Disability can

be seen as a response to biomedical models that locate the cause of the

disabled experience within the individual; in this case the individual is seen as possessing the impairment or attribute (Tregaskis 2002). SMT understands that disability (and especially meanings of disability) lies outside of the individual and in the socially constructed world. Experiences of handicap and disability are not the fault of the person, or as the most important characteristic, but are better understood as the result of a disabling social environment.

Altman explains that the social model defines disability as a "Limit or loss of opportunities to take part in community life because of physical and social barriers (Altman 2001:103)." Marks explains further: "The social model focuses on citizenship rights and the way in which social organization oppresses disabled people. Impairment only becomes disabling because of social structures and organization (Marks 1999:77)." Impairment here is distinguished from disability as a state of being; for example, the presence of a chronic disease or the absence of an arm or leg is merely a state of being until "...social organization oppresses..." the person with the impairment (Marks 1999:77).

The real value of SMT in my research can be better understood by understanding the roots of the framework. The civil rights movements of the 1960's and 1970's, as well the mass de-institutionalization of people with disabilities are often regarded as events that set the stage for the birth of SMT (DeJong 1979). Some scholars maintain that the agitation for rights for disabled people was its own civil rights movement, akin to those carried out for women's and minority rights (Driedger 1989).

During the 1970's, disabled people, service providers and others began to mobilize in resistance against the parentalistic and ubiquitous biomedical model of disability and rehabilitation. In Great Britain, disabled persons organizations were making their voices heard (Union of the Physically Disabled Against Segregation 1976), while scholars were articulating elemental principles of SMT (Finklestein 1980; Oliver 1983). At roughly the same time, the Independent Living (IL) movement was picking up momentum in the US and Canada. Again, a group of disabled people, service providers and other organizations were proactively addressing the problem of rehabilitation medicine in the experience of disability (DeJong 1979).

While the idea of disability-as-social-construction may not seem very novel in the context of current academic anthropology, it was a pivotal and emancipatory concept as articulated by consumers in the early days of SMT. This articulation was a statement of resistance from a traditionally subjugated group (disabled people) to a state-supported "scientific" institutional power (biomedicine) about voice, human rights and entitlement (Charlton 1998).

In spite of this resistance-turned-theoretical model (SMT), biomedicine continues to be a culture of status and authority when it comes to the administration of services for disability. Elementary and high school students in Manitoba who require special accommodations as a result of impairment can only gain access to such accommodations once clinical assessment is complete (Gerald Farthing, personal communication 2003). Students at the University of Manitoba must also provide documentation authorized by a clinician in order to

receive accommodations from the Disability Services Office (Janalee Morris-Wales, personal communication 2004).

The consumer-centered approach of SMT is central to an understanding of how postsecondary students with disabilities access education. Service professionals, clinicians, universities, and students with disabilities are engaged in relationships of status and authority as accommodations are provided or not provided. SMT is best able to understand these politicized relationships, and indeed, is best suited to my research.

The nucleus of SMT, as I see it, regards disability as a fundamentally social experience in an environment of physical, temporal, socio-cultural and institutional construction. The experience of disability, while informed by impairments and other culture-independent aspects of identity, is still largely social, and therefore connected to issues of status and authority. It is the socially constructed environment where I will focus my research in order to uncover the answers to my research questions.

The Built Environment

Plugging into the social model of disability, I take the concept of the built environment (BE) as my second theoretical underpinning. While this concept has often referred to the physical architecture of spaces, I expand it here to include social, temporal, and administrative spaces.

Having said that, I must acknowledge the application of this concept by the field of academic architecture to issues of disability. During the International Year of the Disabled (1981), a research colloquium was held in Sweden titled

"The Built Environment and the Handicapped". Goldsmith presented a paper at the event where he outlined the role of the architect as an "enabler" (Goldsmith 1981). Although his argument sounded a lot like those put forward by rehabilitation professionals, Goldsmith's contribution is key. By suggesting macro-environmental changes to public space as an option to work in tandem with the micro-environmental adaptations for individuals, Goldsmith helped to pull our understanding of disability into the social and away from the individual. Architects are designers of physical space only, yet the idea of enablement through macro-environmental design is worth carrying forward. In the same way that buildings are designed by social actors and institutions, so too are policies and practices designed. The professional skills required for such design may differ, but the constructions produced are nonetheless features of an environment occupied by society.

The built environment represents as manifest the beliefs and values of the society that creates it. Campus quads, social conventions of proximity, calendars and funding applications are all examples of the culturally constructed; they represent a *grand built environment* designed *by* people *in* society, and they are representative of the beliefs and values of those people. Moreover, if society is politicized in terms of the distribution of status and authority, so too are the constructs produced by society. Put another way: "Design aesthetics reflect certain idealized assumptions about the inhabitants and users of the built environment. In different ways, designer "ablism" is a central feature of classical, modern and post-modern architecture (Marks 1999:82)."

Moreover, the BE can also be seen as the manifestation of the recent global forces of transnational capital and a shift away from manufacturing industry to service and information based industries (Knox 1987). In other words, it is not just local social forces that can dictate notions of form and function, but in addition the global distribution, exchange and consumption of resources also plays a role. Laws views the built environment in yet another way; as the manifestation of oppressive knowledges in urban space, and as sites for the resistance of one group against another (Laws 1994).

Knox, Laws, and Marks tend to focus on the physical built environment in their analyses. In order to properly create foundations for my analyses, I must expand this notion. For the purposes of my research I consider the built environment as the socially constructed world of human interaction. In other words, I follow scholars such as Fichten and include buildings, urban planning, transportation, time, calendars and policy as part of my understanding of barriers to access (Fichten 1995). Fichten identifies what she calls "hidden barriers" in all of these places—from interpersonal interaction between students, instructors, services providers and government, to social policy and funding options for students, to the physical structure of university campuses.

Again, this study has been open to documenting *all* barriers and aids to accessing postsecondary education. I make no presupposition about the types of barriers or aides to access that are encountered by disabled students. My concept of the grand built environment (GBE) is designed to allow for any possible experience of barriers expressed by students with disabilities. As well,

the (GBE) is a concept that aptly interfaces with the SMT; by taking into account the politicized nature of socially constructed time and space, the (GBE) leaves room for analyses that address political actors/designers such biomedicine, government and postsecondary institutions.

Disability and the Anthropological Literature

Disability studies (DS) has emerged recently from "intellectual roots in the social sciences, humanities and rehabilitation sciences (Albrecth, Seelman, and Bury 2001)." The Society for Disability Studies describes its disciplinary namesake as being inter-disciplinary; as understanding disability as a social construction; as having a cross-cultural and multinational perspective; and as encouraging the participation of disabled people as scholars and students (The Society for Disability Studies 2004). The Society also locates disability in context as a feature of human experience on par with race, gender, class and sexual orientation (The Society for Disability Studies 2004).

Disability studies and the anthropological approach have been late to marry (Ingstad and Whyte 1995; Kasnitz and Shuttleworth 2001). That said, anthropology has much to offer. The foci on "otherness", social construction, cross-cultural analysis and the way societies differentiate power are all features of ethnographic engagement which make an anthropology/disability studies marriage more than promising (Kasnit and Shuttleworth 2001).

And indeed, this marriage has produced valuable contributions to both disciplines. For example, the anthropological concept of social liminality has been used by scholars such as Murphy and Willet. These scholars explain that

the experience of disability lies in between the "normal" physical experience of health and functionality on the one hand, and the illness experience or "sick role" on the other (Murphy et.al.1988; and Willet et.al. 2001). Still others have taken more recent concepts such as embodiment and reflexive ethnographic practice as seed for investigating disability (Colligan 2001).

Key issues in recent study of disability have included social stratification (Jenkins 1991), globalization (Enns, Krassioukova, and Derksen 2004), and feminism (Boylan 1991; Kittay, Silvers, and Wendel 2002; Morris 1996). Feminism represents a particularly important case of the intersection between disability studies and other disciplines. Feminist approaches tend to see disability as creating a dual problem for women who are already in positions of patriarchal oppression (Boylan 1991; Wendell 1996, 1997). I believe that an understanding of this dual problem is very important to understanding why and how disabled women engage in postsecondary education. Indeed, several female participants highlighted issues of gender and parenting as connected with their experiences of disability.

Studies of disability and postsecondary education are also prolific and relevant to my research. The Canadian Center on Disability Studies (CCDS) produced their *Phase One Report* on the transitions from school to work experienced by postsecondary students with disabilities (CCDS 2003). The study examined forty students and nine service providers at postsecondary institutions in four Canadian Cities (including Winnipeg, where eighteen of the forty students attended) (CCDS 2003). Ten of the forty students in the research

were male, thirty were female; twenty-eight student participants were under the age of thirty-five; just over half of the students reported their 2001 personal incomes to be below $10 000 CDN; finally, twenty-six of the forty participants reported attending and graduating from universities, unlike the others who completed programs at Colleges or other institutions (CCDS 2003). While focusing on post-program employment, the CCDS study did explore issues and experiences faced by students during their programs. Program choice, disclosure of disability, reasons for success, obstacles and educational aspirations were among the topics queried on in the research (CCDS 2003).

Scholars outside of Canada have also been active in recent years; Holloway (2001) used semi-structured interviews to study postsecondary students with disabilities in the UK. As part of her research, Holloway highlights students' experiences of accessing financial support, encountering administrative departments and accessing buildings and facilities (Holloway 2001). It is important to note the context-dependent recommendations made by the research participants in Holloway's study. In other words, the policies and administrative practices in the UK impact directly the recommendations made by students interviewed (Holloway 2001).

Low used an ethnographic approach (unstructured interviews and a focus groups in specific) to investigate the university experiences of nine students at "a large Canadian University (Low 1996:235)." Low's analysis focuses on the apparent contradictory nature of the negotiation of disabled and non-disabled identities by students with disabilities (Low 1996). With a focus on the social

interaction of "deviant" identities in the general student population, Low pinpoints integration of such students as problematic (Low 1996).

A more intensive undertaking was conducted in the research of Hill (1992). Using a three part survey questionnaire, Hill collected data on services (offered by the universities) for students with disabilities at twenty-seven Canadian universities (Hill 1992). The surveys were mailed to, and completed by, the Coordinators of services for students with disabilities at each of the universities in the study (Hill 1992).

The research proposed in this document fits appropriately into the above context. The focus, unlike the CCDS report, will be exclusively on the barriers and aids encountered *during* the participants' experiences at university as they access education. Although work has been done elsewhere in very recent years, it (as in the case of Holloway's work) has yielded site and state-specific recommendations disconnected in many ways from the Canadian context. In a significant departure from the work of Low, this study intends to produce a more focused and applicable knowledge (that may be used to inform policies and procedures) based on the experiences and advice of students with disabilities. In an even more significant departure from the work of Hill, this research will not engage service providers, instead focusing on student participants. Moreover, the data collection methods will be more open-ended than the instrumentation of a survey questionnaire.

The multi-disciplinary approach, the focus on disability-as-social-construction, the importance of reflexive research conducted by and with

insiders, and the broad international/cross-cultural gaze are key features of disability studies. Anthropology and the ethnographic is both enriched by and mirrored in disability studies. The ethnographic literature on experiences of disability is vast and varied.

Summary

Through the use of Social Model Theory and the concept of the Built Environment I aim to situate my research into the context of other similar endeavors in anthropology and disability studies. My approach is designed to be open to all possible answers to my research questions. The specific design and research instruments are described in the next chapter.

In addition, I hope to expand on the theoretical components of SMT and the GBE. I have explained above how these components have been formulated and used by scholars and citizens. Below I will explore how the participant narratives bring other features to bear on how disabled people interact with the GBE and on the nature of disablement through social construction.

Chapter Three: Research Methods

The Research Setting and Participant Population

A medium-sized Canadian university, the University of Manitoba, was the site of my research and inquiry. I conducted fifteen semi-structured interviews with students. All participants were enrolled in studies at this university during their participation in the research. The fifteen represent a wide variety of demographic and experiential cases. Appendix 1 lists participant pseudonyms and general features.

Participants began approaching me immediately after the recruitment was undertaken. They ranged in age from eighteen to seventy-one years old, five were male, and ten were female. Over half of the participants were over the age of thirty. All but three were enrolled in bachelor's-level programs; the others were engaged in MA and PhD programs. Seven participants were married at the time of the research. Of the unmarried participants, three lived with their common-law partners. Six of the participants had children, although two of these people had adult children.

In terms of ethnic origins, the participants were all but homogeneous. Thirteen were Euro-Canadian, one was an immigrant from Eastern Europe (Jennifer); another had recently emigrated from Latin America (Carlo); and the other (Norma) emigrated from South America more than a decade ago. Carlo, Jennifer and Norma all learned English as their second or third language.

Participants qualified to be a part of the research if they were at the time of the research, or within five years, enrolled in any program at the site university. Participants also had to be eighteen years of age or older in order to be involved.

The research setting was a medium sized Canadian university with between fifteen and twenty thousand full time students in attendance. The campus is home to undergraduate, graduate, and health sciences programs. Like almost all Canadian universities, services exist on-site for students who have documented disabilities.

Participant Recruitment

I recruited participants in two ways. First, I posted large notices throughout the campus' central building. The poster can be viewed in Appendix Two. The second recruitment tool was a letter sent electronically to a list of all students currently registered at the campus office providing services to disabled students (this letter can be found in Appendix 9). While the poster would no doubt have been inaccessible as a recruiting device for students with visual impairments, the emailed letter may have offset this exclusion. Students who are blind or visually impaired typically have access to screen-reading software for their computers in order to access text messages. Having said that, there may have been visually impaired students that were not on the Disability Services distribution list, and that would therefore have been excluded from the invitation.

Over 20 prospective participants responded over a period of four months from October 2004 to January 2005. I corresponded with these people through telephone and email. Some interested students fell out of touch and did not

respond to my successive attempts to set up interviews. Other participants became interested after the research stage of the project was complete. In all, fifteen students participated in interviews.

Research Design

My research design was based on ethnographic methods. I set out using qualitative methods (semi-structured interviews and participant observations) to document participant experiences. Participant observation proved to be unsuccessful; participants were more interested in the interview context. My approach helped create open-ended encounters where participants could express themselves with few confines.

I was only focused on specific events or incidents inasmuch as they could help me get at the way participants created and interpreted the meanings of these experiences. In other words my research was not about uncovering how many times students had difficulty receiving their accommodations or how often they found support from off-campus organizations. Rather, these specific events and incidents are valuable to my analysis because they reveal how students understand and interpret their disabilities in the postsecondary context.

I identified with many features of my participant population from the beginning because I am a university student at the same institution because I am a university-aged Euro-Canadian, because I speak English as my first language and share much of the cultural history of the participants. To me, the people I talked to were not "exotic others" whose "heads I had to get into". Rather, I

viewed the participants as people in my own culture and society who differ from me in a variety of ways, and specifically in terms of their experiences of disability.

The open-ended flexibility of the research encounter offered me the opportunity to keep with an important ethnographic method and proceed inductively (Emerson et. al. 1995:166). In other words, I was not attempting to find instances in participant experience that necessarily fit into pre-existing theories. Instead, I was building theory (or adding to existing theory) on the meanings of the disability experience.

Ethical Considerations

The research proposal for this project was approved by the Joint Faculty Research Ethics Board of the University of Manitoba. Several factors were considered and addressed in the interest of making this research ethically viable. Free and informed consent was obtained from each participant at the beginning of the first interview encounter (the form for informed consent can be found in Appendix. Participants were given the opportunity to ask questions about the research and their role. In the one case where an American Sign Language (ASL) interpreter was employed, a separate agreement of confidentiality was read and signed by the interpreter (the form can be found in Appendix 5). Finally, two transcriptionists were hired to transcribe the interview audiotapes. The transcriptionists each read and signed an agreement of confidentiality (see Appendix 6).

During the research project I had been employed as an invigilator and in-class note-taker at the University of Manitoba office of Disability Services. This

position had afforded me the acquaintance of several students registered with the service. As part of my ethics protocol approval, I submitted a memorandum of understanding to my direct supervisor at Disability Services (Janalee Morris-Wales) and copied this letter to Dr. Lynn Smith (then the director of Student Advocacy/Student Resource Services at the university). This document (Appendix 4) spelled out the nature of my research, my employment with the Disability Services Office, and the steps I would take to maintain my responsibilities as both employee and researcher.

After interview data were collected and before analysis was complete, my role at the Disability Services office changed. I withdrew from my position as invigilator/note-taker and took the position in the same office as accessibility advisor. In this new position I had access to confidential student files that were maintained by the office. At the time my position began I had conducted fifteen interviews with student participants and was attempting to interview others who had come forward with interest in the research. I consulted the chair of the JFREB at this time for advice. After a couple of discussions with the chair and with my own thesis committee, I decided to discontinue data collection—this included both any new initial interviews and any follow-up interviews.

Some participants in my research were also registered students with the office of Disability Services. In order to assure these participants of my intentions and their rights to confidentiality and anonymity, I provided them with the opportunity to give ongoing consent. The form for this consent can be found in Appendix 7. I assured each participant that I would not access any privileged

information through my employment in order to further the research. Moreover, I advised all interested participants who had not yet been interviewed that I was ending data collection as a result of my new role as a service provider.

Roughly 600 students were registered with the office of Disability Services at the time of the data collection phase of this research. While this is a relatively large number of possible participants (made larger by the students who are not formally registered but who could qualify for services), it was not reasonable for me to guarantee absolute confidentiality and anonymity to the participants. Rather, I assured them that I would take steps (some of these are outlined above) to ensure as much confidentiality and anonymity as possible. In my analysis and display of participant interview narratives I have made various attempts to continue to hide their specific identities from being noticed. In some places I have referred to a student's disability in vague terms, in other places I have changed or removed the names of such features as specific courses or instructors. In this process I have tried not to diminish the integrity of participants' accounts while preserving anonymity.

Qualitative Interviews

The bulk of my research data was collected during semi-structured, in-depth interviews. Interested participants were invited to choose a location where they felt comfortable and at ease. Options such as private classrooms, coffee shops and private offices were given to the participants. I met the fifteen students for the interviews on campus in a variety of such locations. I asked three of the participants to meet for second interviews so we could complete the questions

and discussion involved. On average, interviews lasted between forty-five and eighty-five minutes.

After participants had read and signed the consent form I began the interview by explaining the research in greater detail than displayed on the recruitment poster or the consent form. The questions on the interview schedule (see Appendix 3) were used as a guide. Often participants would begin answering one question, and address several others through their elaboration. It was never my intention to document specific incidents and locations experienced by specific participants. In other words, the interview was not a fact-finding encounter. Rather, I wanted participants to express thoroughly their understandings and emotions regarding the experience of disability.

Data and Analysis

All but one of my fifteen participants agreed to have their interviews tape-recorded. The taped interviews were transcribed by two professional research transcriptionists. The interview that was not recorded on tape was documented on paper. I kept various journal notes during the research process in order to facilitate my memory and to act as a check against any biases that may have emerged later in the analysis phase. Once three interviews had been completed and transcribed, I began broad coding and analysis in order to draw out relevant categories that would later become my themes. The list of categories grew rapidly as I coded successive interviews, and I kept it relevant by using my research questions and interview schedule as a guideline.

It bears mention here that the participant data are not intended to be a representative sample of what all university students with disabilities experience. Rather, the selected participant experiences may shed light on possible areas which are worth more serious investigation and help to build our overall theoretical understanding of the topic of disability and postsecondary education.

Summary

My research was focused on ethnographic data collection in order to document and interpret the experiences of postsecondary students with disabilities. After I received ethics approval, I conducted intensive semi-structured interviews with fifteen participants over three months. I analyzed the data after all interviews had been completed.

Character Sketches

The fifteen research participants had much to tell me. Before I present and represent their voices I need first to provide some "character sketches" to help orient the reader.

Brad: 31-year-old man, single with no children, BEd program.

Brad appeared to be a confident and self-assured man. He has been active in disability advocacy and displayed some strong yet measured opinions on accessibility in postsecondary education. He is in the later years of his program and had as much to tell me about his personal social experiences with his disability as he did about his opinions about disability and advocacy.

Carlo: 44-year-old man, married with children, BSC program.

A mature student, Carlo speaks English as a second language. He juxtaposes his current University of Manitoba experience with his past experiences in South America. University has been difficult for Carlo and his family. He worked very hard in many science courses and related to me that his wife was a very big help to him during his program.

Charlotte: 24-year-old woman, single, no children, BA program.

Charlotte thinks actively about disability and activism in the postsecondary context. For her, understanding disability service provision in university requires the context of accessibility services in high school. At the same time, she brings levity to her experience through a whimsical and subtle attitude toward

advocating for her own accommodations. Her whimsy is replaced by persistence and tenacity when she advocates for wider changes to university accessibility.

Geanette: 31-year-old woman, single, no children, MA program.

Geanette has had many postsecondary experiences in different programs at more than one institution. Her experience has been varied and sometimes very difficult. She emphasizes a narrative of resilience in her account of the disability experiences with a focus on how her high school and undergraduate encounters have made her tenacious and disciplined in her current program.

Inez: 48-year-old woman, married, no children, PhD program.

My interview with Inez moved back and forth between ethnographic research and one-on-one social science seminar. Inez has advocated for her own accommodations many times and, as an instructor she advocated for students in her classes who have disabilities. She has a well thought-out and systematic approach to dealing with her disability, and her thoughts are well-articulated when it comes to her rights as a student with a disability.

Jason: 19-year-old male, single, no children, BSC program.

Jason was in his second year at university when I interviewed him. He lived with his family and cited them as a major support for him while he attended classes. In terms of his experiences as a disabled student, Jason found that physical barriers (doors without automatic push-buttons, snow-covered paths in the winter) were his biggest concerns.

Jennifer: 23-year-old woman, married, no children, BA program.

Jennifer uses American Sign (ASL) as her first language. She does not see herself as a person with a disability. Instead, she regards her deafness as a quality of diversity that gives to her different strengths and weaknesses than those experienced by people who are not deaf. While she wishes that other students on campus would be more engaged with her, she finds a strong community in her family and the community of other people who use ASL.

Larissa: 32-year-old woman, married with children, BSC program.

Larissa related her experiences with frustration and perseverance in much the same way as Geanette. Where Geanette cited her parents as a main support, Larissa cited her husband. Larissa studies full-time while her family is supported by one income. In addition to her academic responsibilities, she finds the role of mother and partner challenging at times.

Lisa: 24-year-old woman, single, no children, MSC program.

Lisa has much initiative in finding services and accommodations relating to her disability at university. This is not to say she has an easy time of it, but that she always winds up with what she needs. In addition to conventional supports for disabled students, Lisa finds that her boyfriend contributes a great deal to her academic success.

Liz: 36-year-old woman, single, no children, BFA program.

Liz appears as an interesting and quirky fine arts student who is very interested in expressing herself through many mediums to many audiences.

When it comes to her mental health disability, Liz is an active advocate and has many strong opinions about society, stigma and accessibility.

Nicola: 40-year-old woman, married with children, BA program.

Nicola finds a great deal of support from her family as she attends classes at the university. She spent a lot of time with me in the interview explaining the nuances and intricacies of how her mental health disability impacts her academic experiences.

Norma: 71-year-old woman, married with children, BA program.

Norma appeared to me as an intelligent, confident and soft-spoken woman in her early seventies. She told me how she was attending university not to build a career, but to keep her mind engaged as she grows older. She described a colorful and full life to me—a life that took place before she began attending classes at the university. For Norma, her disability experience with visual impairment is very much interwoven with her experiences of aging.

Robert: 21-year-old male, single, no children, BA program.

Robert was very quiet during the interview and remained interested but guarded. Robert's mental health disability relates to key experiences in his past. For him, these experiences and the consequences of them have more importance than his disability itself. He finds university accessible and feels he is well accommodated.

Serge: 44-year-old male, married with children, BEng program.

Serge seemed to me to be wise beyond his years. He explained his

disability along with his coping strategies with calmness and deliberation. He has had several experiences advocating for himself in order to receive services on campus for his neurological disability. In spite of this, Serge showed no intense emotion or frustration.

Treena: 18-year-old woman, single, no children, BA program.

Treena appeared to me to be an enthusiastic student in the social sciences who has been actively building her identity as a person with a disability for as long as she can remember. She is actively focused on the way her personal disability experiences intersect with what she is studying in her program about society, disability and difference.

All participants had one obvious feature in common: they were interested in this research and offering me their stories and experiences. In answering my research question I have not been able to acquaint you with these people in the way that I know them. What I hope you will take away from this section is a sense of the various personalities and how this impacts the narratives that follow.

Representation and Voice

In representing participant experiences I wish to provide expansive description. I have done this by providing many detailed quotes from participant interviews and from my other encounters with these students. Where appropriate, I contextualize these quotes for clarity. More often however, I leave participant accounts as free-standing as possible in order to give as much voice to them as this form allows.

The extent to which I have chosen to represent participant voices is a function of my research question. This representation is also a function of where the data has taken me. In other words, as I build theory out of the participant descriptions and experiences, I am selective. Hertz explains:

> The respondent's voice is almost always filtered through the author's account. Authors decide whose stories (and quotes) to display and whose to ignore. The decision to privilege some accounts over others is made while developing theories out of the data collected (1997:xii).

The research data collection was informed by two specific research questions. This fact limits the range to which the data can be represented, but it does not mean that other interpretations and representations are not possible.

I am interested in building theory about how postsecondary experiences are lived out by people with disabilities. I am also concerned about doing justice to the participants' delivery of narrative. Put another way; the participants have all been exposed to a university education similar to my own. As they articulate their experiences, participants use many tools of explanation familiar to me and my ilk in the social sciences.

I want to expose you to a landscape of experiences and understandings. The most valuable and striking themes to come out of my research encounters were as follows: the disability experience; encountering the institution; advocacy; barriers, supports and personal strategies; and advice to other students with disabilities.

Where my own voice appears in quotes from the research, I use my own first name. In all instances where participants are referred to I use the pseudonyms listed in the previous section.

Chapter Five: The Disability Experience

At the centre of my research and at the centre of participant interviews was the experience of having a disability or being a disabled person. Each participant had something to say about their own particular experience. Two key dimensions emerged from the data on participant experiences: diversity across cases, and the impact of context on the disability experience.

Diversity and Variability

Diversity across cases of disability experience was evident even from the pre-analysis stage of the research. Lisa spoke about her disability experience played out specifically related to her physical experience of campus as follows (I asked her if fatigue was an issue she had to deal with as part of her disability):

> Big, big fatigue. That's when it [my disability] reoccurred in university, that was the biggest thing that I couldn't stay awake in class. Uh, I'd try as much as I could but I can deal with the uh, actual pain using medication but the fatigue is the biggest problem. ...The rheumatoid arthritis has been a little harder to cope with. Mobility, I mean in the first couple of years I was dealing with it here at the university it wasn't too bad because I was all in one building [with my classes]. So it was...I could use the elevators. I could drop a couple of courses, now engineering I am, with one of our buildings gone, I am all over the place [attending class in multiple buildings].......like running across campus type of thing. It takes me a little bit longer. Um, especially when [my disability is] really affecting my joints. I'll be limping across.

Lisa goes on to talk about the social experience of her disability when dealing with instructors and disclosing their disability:

> **Brian:** What do you feel is the worst that could happen when it comes to letting a prof know?
>
> **Lisa:** They treat me differently.

> **Brian**: *How so?*
>
> **Lisa**: *It's really hard to quantify. I know they treat me differently because I am a girl.*
>
> *...The invisible disability is a lot harder to deal with than, in my opinion maybe then a visible disability. Even though it may even...a visible disability may restrict me even more but the profs can quantify it and then they go yes, ok, you deserve this [accommodation]. Whereas they don't know if I actually deserve [an accommodation for a disability they cannot see].*

It is important to point out how Lisa believed her instructors to be suspicious of her entitlement to disability related accommodations. Her observation was that they had this suspicion because they could not themselves observe her disability. Her comment about being treated differently will be visited shortly in light of how gender and disability experiences interconnect.

Norma explained during the interview how her vision disability played out for her in two significant ways. First, she experiences it socially in the form of embarrassment:

> *...I don't like anybody to know that I can't see red or recognize [their face] and all that. ...I usually tell the students [I know] if they see me on the bus or anything call out to me or even if they see me on campus, call out and uh, so they understand.*

Secondly, Norma has a problem experiencing the physical space of campus:

> **Brian**: *Right. So getting around campus, like walking to and from class and stuff like that, do you find that's a problem for you?*
>
> **Norma**: *Um, just seeing the numbers and the staff on the doors and if there's no clear indication as to where something is, or an office, um, then I am in trouble. (laughs) I don't know where to go or...I get lost quite easily in the Tier [building]...*

Norma's and Lisa's experiences show the juxtaposition of physical and social experiences of disability. Both women had different disabilities, yet both

found difficulty in their encounters with the physical space of campus. At the same time the two participants emphasize the social experience of their disabilities. While this experience did not appear as intense for them as their physical ones, Lisa and Norma are conscious of how they are regarded by others (students and instructors) as they engage campus and their educations.

Some participants seemed to experience the social dimensions of their disabilities with ire in place of embarrassment. Treena experiences the visually conspicuous nature of her disability as follows:

> *Brian: So what I mean, you mentioned before you talked about the visibility of your disability...how have you experienced that?*
>
> *Treena: Um, I think I should have a shirt that says stare at me please because that's [my disability is] an interesting thing.*
>
> *Brian: People do or they don't?*
>
> *Treena: They do. Like a guy was staring at me and he was walking as he was staring and he ran into a wall. Like, be a little more discrete right? And the thing with my disability is you have no idea what condition [caused it] because it's not visible.*

For other students the experience of their disability did not involve aspects like the physical and social ones described above. Liz describes how she experiences her mental health disability in her education at university (here is an excerpt from her answer to a question about her overall experience at university):

> *...Well there are more days that I feel like quitting then I do feel like going on.*
>
> *... I don't have many happy days. You know, how the average person is not happy then they are sad?*

> *...I am just lucky that I can get out of the house some days. I am just lucky that I can get out of bed that day. I am lucky that I can get down and see my doctor that day.*
>
> *...I cannot get up for seven o'clock in the morning and just...that does not work. Like when I have to do exams for example, like my exams this year are scheduled at ten o'clock. That's murder for me. That's murder. That's just too early because my medications are still really thick in my system and I am really groggy. And I am very uh, groggy. It takes me a lot, like I usually, if I am having a good day and I am stable, I need to sleep in. And I am not out of bed until eleven o'clock and then I can think.*

For Liz the experience is not related to the physical or social realities of campus, but instead focuses on the temporal aspects. Schedules and timing are a large feature of how the university operates. For Liz, it is the challenge to meet this feature that characterizes her experience.

In separate interviews Inez and Serge describe how they experience multiple disabilities outside of the physical and social spaces of campus. Part of their descriptions follow:

> *Inez: Seriously. Um, when you take all the medication that I am required to take, your concentration drops. Memory problems. And I am suffering with some cognitive word finding problems. Some of the meds I take create other problems. So, it's like I am functioning in a fog most of the time.*
>
> *Serge: ...Well ok, obviously there's those [medication] side effects I have to deal with and the seizures themselves obviously uh, as it relates to school so, you know, when they occur I have to catch up with the material that I've fallen behind on.*

Inez and Serge did not refer to their disabilities in specific when relating their experiences. Instead, they focused on the impact of treatment (medications) as the major problem encountered. Like Liz, Inez and Serge do not cite the physical or social aspects of campus as the center of their experiences.

The people who shared their experiences in this research each drew their focus to different aspects of their disabilities and the environment around them. Some cited the physical, social or temporal aspects of university education. Others characterized their experiences not in terms of external features, but of internal and personal difficulties. This is not to say that the latter group of participants was willing to take on their disabilities as their own problem.

The experience of being disabled and attending university was also described as intensely emotional and frustrating at times. For some students this frustration was the direct result of acquiring accommodations from instructors and service providers. For others, the disability experience was emotional in the university context because of day-to-day encounters with the physical and social space of campus.

The research participants were a diverse group of people in many respects, not just in terms of their disability experiences. Other dimensions of these peoples' lives (family, gender, race, class) all impact the way in which they experience their disabilities.

Context

The nature of participant experiences was set into and impacted by the contexts of family, gender, ethnicity and class. Having received positive encouragement from parents and siblings during childhood can of course provide self-confidence later in life. This self-confidence became a critical part of Geanette's experience with her disability. After telling me much about her personal history and disability, she explained how her family came into the picture:

...my parents always had undying support for me and an incredible belief that I was the most intelligent person in the world and if I wanted the sun, the moon, the stars and the skies on a silver platter I would get it because I can achieve whatever the hell I want because I am Geanette. And so there was never any question about support or love or belief. And so because of that, my father...like my father didn't go to university and I think he always wanted [my brother] and I to go so he would just be like oh well when you finish high school you'll got to university and so I just always accepted that.

Geanette describes her disability experience at university as many difficulties followed by perseverance. She explained time and again that it was her parents' encouragement that allowed for her to become the tenacious student she now is. According to Geanette, it is that tenacity that allows her to succeed at university in spite of having a disability.

While the female participants did not specifically characterize their disability experiences in terms of their gender, it was nonetheless a contextualizing factor. In an excerpt listed earlier, Lisa touches on how her femininity confounded her understanding of her how her disability was perceived by others:

> **Brian**: *What do you feel is the worst that could happen when it comes to letting a prof know?*
>
> **Lisa**: *They treat me differently.*
>
> **Brian**: *How so?*
>
> **Lisa**: *It's really hard to quantify. I know they treat me differently because I am a girl.*

Lisa expressed to me that when she perceived her instructors treating her differently from other students (taking it "easier on her"), she knew this had something to do with her gender, but she did not know if it had anything to do

with her disability. That said she suspects that disclosure of herself as disabled to an instructor may result in different treatment. For her, the personal features of her disability and her gender made (or could make) the instructors' treatment of her appear ambiguous. This observation is critical to understanding how the experiences of disabled people and those of women are similar. Feminist analyses of disability suggest that women who are disabled encounter the double oppression of patriarchy and ableism (Boylan 1991;Kittay, Silvers, and Wendel 2002;Morris 1996). Lisa's experience suggests that where a disabled woman only experiences discrimination for either gender or disability, they are still frustrated by not knowing which one is the case.

For others, disability experience in the context of femininity is less ambiguous. When I asked her about how she experiences her disability on campus, Treena explained to me that she feels unsafe on campus after dark:

> ...you would never ever catch me walking through that quad past dark. Never. Ever. It's not lit at all. Honestly, if you put my arms around my upper and you'll I wouldn't be able to move my arms and they aren't strong enough to get out.

Treena's disability impacts the use of her arms as tools with which to defend herself. Personal safety for women on campuses is a common issue. Addressing safety happens for Treena in an amplified way as a result of her experience with disability.

The interaction between disability and masculinity was highlighted during my interview with Serge. As a result of his disability, he cannot hold a drivers' license. He explained to me how he had to deal with this fact as follows:

...I don't mind sitting in the passenger seat while my wife is driving. I've gone beyond the ego stage part of it years and years ago, but it's just the inconvenience of knowing that, you know, I can't hop in the car and drive to Safeway to get a jug of milk if I need to, so. So that's an inconvenience. And as far as getting to school, yeah, it does pose a bit of a problem but most students take the bus. So, you know, I resign myself to that too.

Serge explained to me that the loss of his drivers' license was, for a while, a threat to his ego, and his masculinity. Although he has addressed this in terms of his experience on campus, he regards it as something he must "resign himself to".

Attending university is a financial challenge for many students. Having a disability often means that one has to take reduced course loads and spread out a program over more years than would otherwise be required. Still others attend courses full time and access community supports in order to offset a diminished income while they attend university. During a detailed description of her experiences at university, Geanette recounts with some ire her frustration over her student debt:

> *...So I have eight years of student loans because of the LD [learning disability]. Not because I am lazy, not because I slacked off. Not because I did anything wrong. I mean there was one year in there that was really, really bad academically and that was because of the depression which was undiagnosed, with the exception of that year, I mean the reason that I have the debt load that do, is because of my learning disability. It's not because I did anything wrong. So then why is it then that I am being financially penalized for something that I had control over.*

The relationship between requiring a student loan as a result of her disability and ending up with debt is clear to Geanette, and unfair.

Larissa shared with me a less obvious connection. A mother and partner, she explained to me that because her family had to rely on one income (her husband's) while she attended classes, she found herself using the food bank from time to time.

Meeting the challenges of course requirements is a necessary part of attending university. Students who do not have a full command over the language of instruction are presented with an additional challenge. As well, students who lived the bulk of their lives in places other than Canada (Carlo completed part of an undergraduate program in his country of origin) encounter challenges related to adapting to another culture. Carlo explains how the language issue presents him with a particular challenge:

> **Brian**: *How long have you spoken English?*
>
> **Carlo**: *Well I've been spoken English for the past thirteen years. Yeah. So there is a problem there. You know, like uh, it's not like I couldn't say ok I can manage the whole thing now, it's not possible, you know? But uh, yeah, it's still a little bit [of a] problem.*

Carlo uses tutors as part of his program in order to address his learning disability. These tutors are invaluable to him as he completes course assignments and exams. How much of the tutoring helps with his language skills in English, and how much helps address his disability is difficult to determine. What is evident is that in terms of his education there is sometimes one solution for several challenges.

While it is beyond the scope of this research to delve more deeply than I have into the relationships between disability and family/gender/race/class, it is

worth considering these key categories of experiential context. Most often, the participants only explicitly focused on the category of family and left the other three categories unmentioned. Yet all participants experienced in one way or another gender, race and class. Disability experiences do not happen in a vacuum. Rather, these experiences happen through bodies that are gendered, and interpreted through lenses of ethnic origin and social class. Moreover, people experience all of these categories of difference (including disability) in social, physical and temporal contexts.

Summary

Participants' narratives show that disablement in the Grand Built Environment is not untouched by actors like students with disabilities. People like Norma and Lisa did not use the language of SMT to explain how they related with the Grand Built Environment of campus. However, they were conscious of the fact that their disability experiences were connected to and influenced by the social relations between instructors and other students. More than this, the participants (like Treena) were very conscious of how experiences of their disabilities were transformed by the physical and temporal environment of campus. Other participants' experiences show how this transformation can happen as a result of other experiences not related to disability per se (gender and ethnicity for example).

The thing to take away here is that the participants are social actors who not only experience the Grand Built Environment, but also understand its presence even if they do not characterize it in an academic way.

As students experience their disabilities in the university environment they encounter diverse and varied emotional states, and come up with equally diverse narratives of understanding. These narratives and descriptions were situated in contexts of the family, gender, race and social class. The participant group was representative of a range of physical, mental health, and cognitive disabilities. There was no single "disability experience" characterized by these students. Rather, key themes emerged in regard to encountering the university itself.

Chapter Six: Encountering the Institution

Universities are, if nothing else, large bureaucratic institutions housed in large architectural spaces and operated on consistent and regulated schedules. Complicated procedures are carried out by staff in many levels of administration, service provision, instruction and support. Students with disabilities encounter the social, spatial and temporal aspects of the university environment in a variety of ways. Of significance in my interview data were the narratives participants relayed that described various encounters with the university. Three categories of encounter emerged out of the data: evaluation, the student body, and politics.

Evaluation

All academic programs at the University of Manitoba require their students to meet or exceed standards of evaluation. The mechanisms that allow students to demonstrate their abilities and knowledge are varied (exams, course assignments, research theses). When a student with a disability is accommodated in order to be evaluated fairly and without hardship, the university carries out detailed procedures that require students to support their request with clinical documentation.

Students with disabilities encounter instructors and other students in the process of receiving accommodated evaluation encounters. For the participants, these encounters were one of the most significant parts of being a disabled person at university. When I asked her about her experiences with courses and faculty, Charlotte pointed out to me how sometimes the research taught in class by an instructor contradicts the evaluation strategy used by said instructor:

...I've talked to Profs at the beginning of the year and at the end of the year and throughout the year, kind of going like okay, but you just finished saying in this class that everybody learns differently yet why won't you put like a short answer, long answer, true or false, I suck at true or false but I'm sure that somebody else would probably do well at that right, and why can't you have multiple different types of, either on the same test or offer different test formats for different people right, cause for myself basically what I'm at is if I have a short answer, long answer test I get an A or like a B+, if I have a multiple choice I get a C, so my minor is Philosophy, may major is Psychology and I have A's and B+'s in Philosophy and C's in Psychology, except for the one class where it was research methods and we had to write essays and then I got an A, so for me the main issue has been, or like the main barrier and the main frustration that has affected me is the fact that like I know how much I learn and I know how much I've gained out of the courses but my grades don't reflect that...

Charlotte is frustrated by how her knowledge and skill is not being assessed accurately by the common modes of testing in her courses. She becomes even more frustrated when instructors in some disciplines seem to disregard their discipline's own lessons and when it comes to their evaluation strategies. She goes further still and recounts an experience with writing a multiple choice exam. She explained further how the exam's format was, to her, arbitrary and unnecessary for evaluative purposes:

...Like I'm in Humanistic and Transpersonal Psychology and the Prof is like, in HEP, which is Humanistic Existential Thingmomological Psychology, the E is for Existential most emphasizes so that's the question and he asks us like, on the last test. We had like ten questions with that same line and then a, b, c, d, e, was like one word, like a big word rather than another word, and they're like descriptive words, and then word rather than word, word rather than word, word rather than word, all of the above, none of the above, or a or b, or c or d or.... ...and you're like, oh but I know what Existential Psychology is, I know how it relates to the things, I know what it most, is most, like what it stands for. I don't know what the fuck this is, like you know, and he himself has stated multiple times in class, he's like well this class really isn't best tested through multiple choice testing, like it would be a lot

*better if you guys had short answer. ...And so I raised my hand,
and he's like yes, I'm like, so why don't you give us short answer
tests. And he's like "well it is easier to give you multiple choice."
I'm so why are you telling us this in class. ...But he's lazy. We're
thirty people in the class, he could give us short answers, he could
get his little slave, like a T.A. and get them to do it for him, like if he
didn't want to mark.*

Charlotte described her own disability as involving the mental processing of the

visual information that is text on a page. Things like spacing in the text, white

space, margins and brightness of paper all impact her ability to process the

information properly. Her narrative above does not focus on this in specific, but

rather focuses on an active observation of how her instructor evaluates the class,

and how this evaluation defines her performance. Whether or not the multiple

choice form of evaluation is a disadvantage for Charlotte because of her disability

is not the focus here. Rather, Charlotte has identified a contradiction and

critiqued the method of evaluation as unfair in general, for all students. The

cynicism regarding institutional procedure and instructor participation is no doubt

shared by some of her student peers. The citation of the procedure as a

disabling practice is perhaps what would set Charlotte's analysis apart from that

of her non-disabled peers.

Beyond taking issue with the method of evaluation and feeling extremely

frustrated, some students feel personally offended. When I asked her more

about her academic experiences, Geanette, related her disability experience

when it came to writing a research paper:

*So, for example when I first came to [the] University of Manitoba I
was doing this research paper and I spent at least 100 hours on
this research paper. Like I was very interested in it, I loved the TA,
you know, really wanted to do well and everything. So I had spent*

at least 100 hours researching this damn thing and so I'd given it to one of my friends to proof read and so she took a look over it and said ah, B, B+, you know, and I was just devastated. Just absolutely devastated because I've never put so much into something and for somebody to say ah B, B+, you know, like to me that was such a dig.

For many students it may feel emotionally painful to spend hours of work on an assignment only to be graded poorly. For a student with a disability this experience may feel more intense. Not only may students with disabilities work as hard as other students, but they may also have supports in place to help accommodate for their disability.

In cases where students with disabilities contest past evaluation as unfair (based on absence of accommodation), they often find out just how important evaluation is to the university. Larissa had done poorly in a course as a result of not having her disability accommodated for. She tried to have mark removed from her transcript—she explains:

...So, I requested an authorized withdrawal [from a course] to get the mark taken off my transcript and they said no. So I brought them my documentation and they said you need further documentation. "We need...well here (on your psychological assessment) it says you're within normal limits or the normal limits are this and you're either above or below we need to know this and we need to know exactly what it is."

Larissa experienced much more frustration before her request was finally accepted. Her experience and frustration show that evaluation at university is a high-stakes process. Both students and the university work very hard to make sure evaluation is fair and accurate. This high-stakes process is often confounded and made more difficult when disability accommodation is requested and/or provided.

Students with disabilities interact with instructors and administrators in order be evaluated in ways that fairly accommodate their disabilities. In addition to this, they interact with their student peers, not only in the way they are evaluated, but in the way they encounter the university in general.

The Student Body (Peers and Competitors)

A second key feature of the university environment that was highlighted by the participants was the rest of the student body. Over 20 000 students attend the University of Manitoba. This group of students encounters each other as supportive peers, associate learners and intense competitors. The students who participated in this research had much to say about their encounters with other students.

Lisa receives exam accommodations for her disability. She tells of how she feels students perceive her as a result of these accommodations:

> *I think that people do evaluate me differently. I think students, if I get a good grade, then they may be like oh, well did she get that because she gets [exam] accommodation? She gets a computer. She gets extended time. So, you know, does she have an advantage?*

Lisa feels like her accommodations are regarded as unfair by her peers who do not receive them. She does not feel that she is being evaluated unfairly, or that she has an advantage over others. Instead she feels like the process of accommodating her disability is mystified to other students.

Other students see the mystification in their peers' attitudes and attempt to correct it. Brad explains one particular attempt:

...especially you know for something like this [my visual impairment] where a lot of people have a difficult time understanding accommodations. A lot of people assume that you're getting special treatment. ...Other students, I think for some people, I think some students, I wouldn't say all students would see it as special treatment, just because they don't understand that it's about leveling the playing field.

When I asked him about his experiences at university, Carlo talked at length about his encounters with peers as part of completing course assignments:

> **Carlo**: *Yeah, other students, you know, don't talk too much. I think they like to keep their distance and stuff like that. So I didn't uh, no I haven't been able to study in groups of something which it could probably help a person like me, you know, to study with other people but uh, other students. Like I even now because one of the courses is um, is very mentally active course. You have to think about some details and stuff like that. And uh, sometimes I don't have that agility we can say to be with some of those problems. And uh, I try to see if I could probably do those assignments of homework with students here in my course but they...that was my impression, nobody told me that but that was my impression, that you were trying to copy what they were doing.*

> **Brian**: *Uh, so they were suspicious.*

> **Carlo**: *Yeah, so they were like oh you know, after that I tried to approach it was the first time and the second time I noticed it was that type of reaction, you know, ok, this is my work and, you know, I don't want you to copy that or something like that, you know. But the instructor made the comment later he said you know, ok, don't do these assignments just on your own. You can get in groups, you can try to do...so I wasn't...like I wasn't cheating or trying to copy something... ...my first uh, something that came to my mind was ok, I've got to deal with this probably getting together with other students. But it didn't work that way. They probably didn't like that. They were probably thinking this guy copying or whatever, you know. ...So I um, with the tutor I managed to do the things, something I could probably do with the students.*

Carlo's ability to handle the complex and demanding assignments of his science courses is impacted by his disability. As his instructor alludes, solving exercise

problems with peers is a good idea for course mastery. While the suspicion of Carlo's peers may not have been related to his disability, the impact of this suspicion is made more of a problem because of his disability.

Carlo's encounter above highlights some important characteristics of the university environment. Peers can be at a support and at the same time be suspicious of unfair competition.

Jennifer uses American Sign Language to communicate but can read lips. She is a warm and open person and sometimes finds that the social environment of campus among students is less than inviting:

> *Brian: What about um, on campus? How do you find the social environment here in relation to being deaf or as being seen as a person with a disability?*
>
> *Jennifer: Really, you know, I don't mind. It's a little bit difficult to socialize uh, because if they find out that I am deaf sometimes people back off a bit. They don't know to sort of know how to interact with me. They don't know how to communicate. When really it's not a big deal. You know, we could write back and forth or I could to lip read or, you know, it's fine but a lot of people; I notice that students tend to become very quiet because they don't want to talk to me.*

By no means does Jennifer feel isolated on campus. Her experience highlights that non-disabled students sometimes find disabilities in general to be mystifying. This attitude impacts the social relationships that students build with their peers who have disabilities.

Jennifer experiences some students as unsure about how to get to know her because of the communication barrier. For other students like Liz, the feeling

is one of other students stigmatizing her. Liz has a mental health disability and explains how she experiences the social environment of campus:

> *... I carry a shame because it's engrained in me and I struggle feeling shame because of my inadequacies. ...What I am finding that people discover that I am different, cause I am different, um, I am very different, and I don't realize how different I am, I really don't. I am very much different, I don't realize these things. ...The stigma is, is that they don't want to catch...they don't want to become depressed. They don't want...they might think you will become obsessed with them. They might think that you might fall in love with them. ...They fear you because they know you're unstable. They know that you're mentally ill so they don't know if you're going to go berserk.*

Liz's experience of stigma is at once internal and external and external to the social context of the university. She finds that the attitudes held by students when it comes to mental illness are similar to those she feels are held elsewhere in society. In other words she feels judged and feared.

Students with disabilities encounter other students on campus as both peers and competitors. When they are viewed by non-disabled students they feel as though these people do not have a full understanding of what disability is and is not. Sometimes non-disabled students are indifferent toward disabled students. Other times they are suspicious of them because of accommodations that may give them an unfair advantage. Finally, some students may want to avoid their disabled peers outright.

The key thing to remember at this point is that students with disabilities encounter their non-disabled peers in several ways. They are alike in the sense that they are all competing for accreditation and engaging in learning through instruction and independent study. They are different in that disabled students

are given accommodations in a way that is mystified to their peers, and in that their disabilities themselves are not always understood.

A narrative related by Brad best captures the complexities of dealing with the university as a large institution from the point of view of a student with a disability. He relates how requiring audio-format textbooks for one of his courses caused a problem for him. He was approached by members of his department's faculty who were concerned about the issue of delayed audio-format material relating to his coursework. He explains the situation as follows:

> ...there is a course that I was in and [a member of] the faculty, I'm not even sure what his position was, but my professor came to me and said you know, this person wants to talk to you about the course, because what was happening is my textbook wasn't, my textbook was far behind, like I was still [waiting for] textbooks or parts of the textbook in June.
>
> **Brian**: This is audio [format]?
>
> **Brad**: Yeah. In June, but the class ended in April, so I was so far behind with that but I was still really trying to stay on top of it and I showed up all the time, and this person pulled me into their office, not my professor, her department head, pulled me into his office and said "you know Brad, do you think you should really stay in the class, like maybe you should get out while the getting's good before the voluntary withdrawal date." And this was just before March; I think it was March 18th. ...Yeah, yeah, and told well maybe you should, well its got to be difficult for a student like you to make it through, and you know it was a very patronizing, very, it was very patronizing and I left that meeting, I left that meeting kind of angry and kind of disappointed. ...Yeah, I said you know I'm just not getting my stuff on time, that's my only problem.
>
> **Brian**: And what did they say to that? ·
>
> **Brad**: "Well then you need to kind of take that up with Disability Services, because obviously somebody there isn't doing their job." And I mean I defended Disability Services. ...Yeah, and so anyways, but this person pulled me in and really, really tried to

persuade me to quit the class and that was, it was very disheartening. And I realize that does not exactly sound like it's directly linked to my disability, but if it weren't for my disability I wouldn't have been in that situation. ...Yeah, and quite honestly I mean if, there was another student in the class, cause I wasn't doing really badly, I mean I was just above, my head was a little bit above, so I mean they wouldn't have pulled another student aside to tell him or her that.

Brad found himself dealing with multiple players in this situation. Disability Services requests audio-format textbooks from off-campus organizations, and provides these materials to students. The course instructor and department faculty member have course requirements and calendar deadlines to be maintained by their students. To be clear, Brad was not expressing frustration at his delayed textbooks, he was instead frustrated because of the treatment he experienced. While his faculty's concern was more than likely well-intentioned, it was uninformed on the issue of the availability and supply chain of audio-format textbooks.

This narrative excerpt demonstrates the complicated nature of the university's institutional structure—multiple people and departments with multiple expectations and resource capacities.

Geanette (31, MA) recounts an incident with booking an exam at Disability Services:

...there was one time that I was taking an intensive, one week three credit course. So it was 8:30-4:30 for six days. And there was one day off in-between there. And so on the first day we got a lecture. On the second day was the very first thing we did was we had a test. ...And when I was doing this one week sessional course my exams were outside of the regular office hours of Disability Services. And so my program advisor actually showed up...like at the time he was the one coordinating the course and it was an

> outside instructor [teaching it] but he was coordinating it. And he
> showed up every day at 7:30 to meet me so that I could write the
> exams before classes started...

Geanette also tells of a less supportive experience dealing with university

administration:

> ...So for example when I first transferred from [an undergrad
> program] in Nanaimo to here; I was going into history and so I
> phoned the receptionist in the History department and I was talking
> to her about which courses to take and all that sort of stuff and I
> said you know, like I have this learning disability and stuff like that
> so I have to be cognizant of how many courses I am taking, what
> the course load is, and that's why I am asking this. And I was also
> asking about which textbooks because I can get my textbooks on
> tape, blah, blah, blah, blah. And so anyway she said "there is a lot
> of reading. Are you going to be able to do that?" And it was like
> yes I can fucking read! (both Brian and Participant laugh) You
> know? But it was just very patronizing. And it...

> **Brian:** Did you say that to her? No.

> **Geanette:** No. No, and I mean I am sure she didn't do it with a
> mean intent. Like I don't get the sense that she was doing it to be
> mean but it was a lack of awareness. And even at the time I took it
> as such, it pissed me off, it didn't insult me, it pissed me off but it
> more made me mad that there was the lack of awareness, not that
> there was the assumption that I can't succeed because that was
> wrong, right?

In her encounters with scheduling a test and being supported by her instructor,

Geanette expresses gratitude. In her experiences learning of future course

requirements, she expresses agitation and understanding. Geanette both

locates and experiences her disability as an important feature in her navigation

through and dealings with the university.

Instructors may encourage students to engage in informal learning

practices as part of course work. While such practices can be valuable for many

students, the informal nature can mean that distribution of support is not uniform.

Many students may need to hire tutors as part of their learning strategies at university. Serge had to hire his tutors because coursework was too difficult to learn on his own. Serge points to his disability as the cause of his problems when he attempts difficult assignments. This characterization of the problem is important because he is able to access disability-related supports to address it.

Brad's expressions of his narrative (displayed above) focused on a more personal dimension however. He felt as though his less-than-stellar performance in the course was unfairly handled because it was connected to his disability and need for supports. It will probably not seem very novel that institutional complexity has personal and individual consequences. What may be less obvious is the locus of Brad's emphasis.

Summary

Student peers, instructors, support staff and administrators come together at a university to form many different relationships of status, authority and privilege. These relationships are negotiated and defined through hundreds of policies and practices. Dealing with the political dimensions of the institution is something in which everyone at a university must engage. For students with disabilities this engagement takes on a specific form. Being evaluated by instructors, accessing accommodations and working with and alongside their peers are all central to how students with disabilities encounter the university institution. In several instances, students talked about these processes as being challenging and requiring a concerted effort and assertiveness.

For the participants, the environment of the university campus was as much social as it was physical and temporal. This is evident in how these people expressed their disability-related encounters with the university. SMT tells us that disablement is often the result of an environment that has not been built with a wide diversity of experiences in mind. When students interact with the social environment of campus they sometimes experience "disablement". But what also happens is an exchange. Students are influenced by the institution they encounter, and in this way, they may adopt disabling beliefs and values or carry out such procedures. At the same time, they may interact with the built social and physical/temporal environments so as to change it for themselves or others.

Chapter Seven: Advocacy

Students in postsecondary environments must navigate complex and diverse procedures within the university context (application, registration, attendance, evaluation, access of support, remuneration, etc.) As well, many students must engage such procedures with outside organizations such as government-sponsored assistance. Added to this, students must find their path in the hierarchy that exists on the university campus. Students, instructors, administration and support staff all have their rights and responsibilities in this environment, and all engage in relationships of accountability and exchange. Such relationships are countless on a university campus, and they are certainly not without conflict.

The participants in this research have encountered their own sets of conflicts and have dealt with them in a variety of ways. The theme of advocacy was one of the strongest in the interviews, and it provides much insight into the experience of disability in the context of postsecondary education. To be clear, by advocacy, I am referring to actions taken by students and others to demand supports and services from and work with administrators, instructors and support staff. Of specific interest in my research is the advocacy for accessible education and disability-friendly programs. Advocacy may be as informal as asking a professor to use a larger font on their computer lecture presentations. Advocacy can be as formal as filling out three applications and providing two supporting documents in order to write a deferred exam for medical reasons. Students may find support and advocates on campus or elsewhere (counselors, parents,

doctors), or students may be their own advocates. Finally, advocacy can happen

locally or globally. An example of local advocacy has been mentioned above—

the deferred exam. Global advocacy can be the efforts of many individuals to

change a policy such as access to elevators on campus.

Brokering Authorities

Advocating for oneself often involves more than just a dyadic encounter.

Students with disabilities must attain clinical documentation from one

professional in order to justify accommodation to another. When I asked her

about her disability experiences on campus, Larissa explained how she found

such a process stressful but fruitful:

> *So, I requested an authorized withdrawal [from a course] to get the*
> *mark taken off my transcript and they said no. So I brought them*
> *my documentation and they said you need further documentation.*
> *"We need...well here it says you're within normal limits or the*
> *normal limits are this and you're either above or below we need to*
> *know this and we need to know exactly what it is." And I said well*
> *why do you need to know that if...I felt like saying to them if I bring*
> *in my broken arm and I show you my broken arm in a cast are you*
> *going to ask for an x-ray? And that's what I felt like saying. I*
> *thought that's really unfair. So I spoke to [the on-campus student*
> *advocate], this was in September. September, October; because it*
> *takes forever. And of course you have the stress of this and you*
> *have to put extra energy and effort and time into this. Yes, it's*
> *important but it's really unnecessary. ...They dragged this out until*
> *November. And basically [the on-campus student advocate and*
> *office of disability on campus], and myself had a meeting with the*
> *associate dean of the faculty, because I went to an appeal, the*
> *appeal denied me. So then I went...I sent up another meeting and*
> *actually the night before the meeting I spoke to my doctor, the*
> *psychologist who did all my testing and I said this is what's*
> *happened. I need you help to spell this out in black and white to*
> *these people who just do not understand or don't want to*
> *understand. So I said you must have this number faxed to the*
> *office by nine o'clock because that's when our meeting is so thank*
> *goodness my doctor did that.*

Of note in Larissa's account is the presence of many players (offices of the student advocate and the campus disability office; her course instructor, the dean of her faculty, and her doctor and assessing psychologist). Also striking is the sense of a long and dragged-out process where many procedures must be followed and many lines of communication must be maintained.

Serge advocated for himself in a very disability-specific way:

> *Serge: You've got to get them [exam authorization forms for disability related accommodations] signed, right? And there's been a couple of incidences where uh, some of the profs suggested to me that they didn't feel that I really needed this. Now they didn't know anything about my condition. They're uh, legally I don't think they have the authority to even ask what my condition is.*
>
> *Brian: No, they don't. They can't get access to that information.*
>
> *Serge: And uh, I didn't offer it to them, but I found myself a couple of times where I didn't butt heads with them but I really had to assert my position in stating that no, this is necessary for me whether you think that I may need to do this or not. Uh, I know.*
>
> *Brian: So you actually engaged in a conversation about it, you didn't just...*
>
> *Serge: Oh yeah. Oh yeah. Yeah. So that occurred a couple of times. Twice. Two professors.*
>
> *Brian: Only two in two years I guess.*
>
> *Serge: Yeah, yeah, so. In that sense most professors are educated now in terms of uh, I think they realize that they don't have a choice in the matter anyway uh, and secondly it's not their discretion. They don't have a medical degree until they do they're in no position to judge whether I should or should not have access to disability and [office of campus disability] and any of the services that they may offer, right? And I stand firm on that position.*

Through his act of advocacy, Serge is confident to invoke one authority (biomedicine) to rebut the authority of his instructor. Serge's assertiveness and

advocacy demonstrate the complicated nexus of disability, biomedicine and postsecondary education. Serge's authority comes from his life experience and personal experiences with his disability (a neurophysiologic impairment). The instructor's authority comes from his position as both an evaluator of students and as a more thoroughly trained and experienced scholar. The authority of the medical doctor in Serge's account is used as a trump; this authority comes from many places. Advocacy can perhaps be seen as a negotiation of the meaning of disability between and among several authorities. These authorities are both invoked and opposed. The ability to understand and carry out such invocation and opposition in fact characterizes Serge's self-advocacy.

One for Many

Some students begin a process of self-advocacy and end up with results that benefit many people, with and without disabilities. Inez (48, PhD.) recalls attending classes at her university in the 1980's and 1990's. Inez has many disabling allergies and the cigarette smoke on campus became a significant problem for her. Here, Inez recounts her problem with the cigarette smoke in the campus' central complex:

> *Inez: Yes. And it was the only building that housed Grad Studies, Grad Student's Association. I couldn't go into the building. I couldn't get up the elevator. So, I started a little rampage of my own. I called [the provincial office of] Human Rights. And I launched a human rights complaint.*
>
> *Brian: What happened?*
>
> *Inez: ...they upgraded all the ventilation systems, they upgraded them, they put additional doors to stop smoke from wandering.*

> *They did a whole pile of stuff. But I got their attention. I was responsible for most of that. I raised hell.*

So we can see the benefit to many as a result of the advocacy for one. In addition, Inez shows us something very important about students with disunities. By accessing her provincial office of Human Rights, Inez demonstrates that she is competent approaching administrators and legislators. In other words, "raising hell" involves not only standing up for her rights, but also doing the leg-work to submit a formal complaint and see a complex process through to fruition. Inez's success at playing a role in her campus' buildings being smoke free had no doubt benefited others without disabilities. The context of disability in this complaint may or may not have provided more weight to her case than would have been given a complainant without a disability. What was evident in my encounter with Inez was the strength of her attitude toward her rights as a result of her identifying herself as a person with a disability.

Some of the participants in this research have engaged in advocacy and intended from the beginning to impact and help more people than themselves. Liz (39, BFa. program) had spent considerable effort and time as an advocate for mental health consumers on campus:

> **Brian:** *So are resources spread too thin [on campus] do you think?*
>
> **Liz:** *I think so. I think so. And what I did was I even advocated for them to get like more space. I wrote a letter and sent it up to the people. You know, like I advocated for them to get new space and stuff like that. You know, I didn't sit around...*
> *...But the point is I am not one to sit around and sort of complain about it. I advocated. I have joined forces, uh, not only did I complain about and advocated against this office from the beginning but then I joined forces with this office and worked together with this office to sort of mould this office to better mental*

health consumers but now it's come to full circle where I feel like it needs some more adjusting for mental health consumers again. So, um, you know, I've had to back up and say listen, you know, some changes need to be made. Um, the other things that I think the university needs to be done like I said, the professors um, I spoke with my fine arts faculty advisor and spoken to the Dean about this is that they need to, and I've spoken to [the coordinator at Disability Services], they need to have workshops on how to educate the professors on mental health and stuff like that. But the Dean said it was a slow process and it's kind of something that you can do the workshops but because, you know, they have legal right not to come to the...

...I think it's a general overall view to be honest with you. I think it's an overall view. I am quite fed up because I've been here for three years and I've had to go and make the changes wherever I go. And I've had to advocate.

Liz expresses frustration and yet emphasizes how she needs to channel this frustration into teamwork and bridge-building. Her own experiences as a person with mental illness are manifested in many places including her need to do advocacy that goes beyond her own particular needs or any single incident. Moreover, her experiences with advocacy have not always paid off in the ways she may have hoped.

Personal Frustration and Overcoming

For many students, self-advocacy was spoken of in terms of the nature of their character. Geanette explained this to me when I asked her about disclosing her disability:

I am very up front with my disability. So I tell people right off the cuff I have the learning disability. I have a hard time spelling. If we put a good spell check into the computer, and as long as I have two or three proof readers that, you know, if I am sending something out into the community that I can have two or three people who are guaranteed to be willing to look over my final product. Then it's not a problem. Then I've done everything I can.

Geanette takes on the responsibility of finding supports for her disability by being a strong verbal advocate at school and in her workplace.

In contrast to Geanette's approach is the more subtle self-advocacy of students like Norma. When I asked about her classroom experiences, Norma explained how she dealt with a difficult instructor:

> *And uh, students would ask questions and uh, he [my instructor] tended to in his replies, his answers, his comments and so forth, he tended to sort of insinuate that they're stupid. And it's a stupid question and stuff like that. And uh, I ask questions in the class and I didn't care and I told him I don't care whether it's a stupid question or not, I want to know.*

Certainly advocacy such as Norma's above is not specific to students with disabilities. The important point of note here is that self-advocacy as experienced by students with disabilities includes experiences of self-advocacy that could just as easily be related by a student without a disability.

When I spoke about the resilience narrative earlier, I showed how Geanette related her past experiences as a child and a teenager. She highlighted an important feature of postsecondary students with disabilities. Adulthood comes with more confidence. Serge displayed this same self-assuredness. Geanette goes further by pointing out just how difficult or impossible self-advocacy had been for her in the past. Yet in her memory she observes the seeds of her present tenacity. And this present tenacity has worked well—here she relates how she handled an incident where her instructor would not agree to her exam accommodations:

> **Geanette:** *So I stormed on in I [said to the admin assistant at Disability Services] I need to talk to [the coordinator]. I was just*

ballistic. And so [the coordinator] came out and I really hope there wasn't anyone writing an exam that day because let me tell you they got an ear full. So I just went ballistic. And I was like "I don't need to fucking put up with this bullshit. I am not paying for this class. I am not taking this class. This class will not show up on my transcript." And so what [the coordinator] did was she kind of calmed me down a bit and she said ok well how about we make extra accommodations. So for example, one of your accommodations would be that you can answer your multiple choice questions in long answer, as opposed to answering them in short answer. And I said ok that's fine. So we came up with these accommodations and I brought the new particular form to this professor.

Brian: *And the partic form [particular form] is?*

Geanette: *The particular form is where it says my accommodations and then the specifics about the exam and then on the back of it, it has the information about writing the exam and what-such. Ok, so that's a particular form. So I take the particular form to the professor and the professor is like "ok I'll take and I'll sign that", and so for about two weeks after that, after every class, do you have the partic form, do you have the partic form? No, no, no. So then finally it's the day before it's the day before, like it's the last class before the exam and he looks at me and he's like oh I sent that in to Disability Services. And I am sitting there and on the partic form it says return the form to the student and the student will return it to Disability Services. I don't know if [the current coordinator] still does it like that but that's how it was done at the time. So right on the form it says that, but I am sitting there and I am [thinking] like you fucker, I have read clearly even though I have a disability, you don't, and you can't even read that piece that was highlighted? So, anyways. So now I am really pissed off. So then I show up to the mid-term at Disability Services, and I look at the partic form and over half of my accommodations are crossed off. She does not need this. This isn't appropriate. This isn't relevant. She does not need this, blah, blah, blah, blah. Now the partic form never says what the disability is, it only has the accommodations. So he had marked off half of my accommodations without even knowing the nature of disability saying that I didn't need that and that he wasn't willing to consent to it. So again, I went ballistic. Absolutely livid. I am not paying for this course. It's not showing up on my transcript. How do I file a human rights complaint. This guy's a dick. [I was] Not a happy child at all. So anyways I wrote the exam, got the mark back. I wrote it at Disability Services anyway. As soon as the marks went up I got 60 percent and I just came back to Susan and*

said absolutely not, no. So I got all of my money back. I filed a complaint and the course was taken off of my transcript. Not even a VW. It never existed. I was never in that class. So because I was like I do not need to put up with that bullshit.

Geanette explained to me that she felt her emotional intensity reach an extreme point. This account displays both anger and satisfaction. While advocacy may be productive, constructive and even necessary in the postsecondary context, it can also be deeply emotional. Dealing with, and standing up to authority is something that began for Geanette very early in her education. She now seems to savor her own hard-earned tenacity. While many university students will have had the experience of gaining tenacity, based on her narratives, Geanette observes her disability as the very site where she gained hers.

Subtle Strategies

The encounters of advocacy related by disabled students are sometimes raw and emotional. Other times it is a simple procedure for the student to merely cite their rights and point to the fact that they have carried out a required procedure. Sometimes much subtlety and care goes into the process.

Brad encountered a problem during his program with his visual impairment and the perceptions held by his supervisors. He explains the complicated nature of advocacy concisely and without hesitation:

Brian: *Did you get a chance to say your piece?*

Brad: *Yeah, I did, and the [problem with my supervisors was solved] so, but I mean in hindsight I probably should have just kept my mouth shut but that was something I kind of weighted against.*

Brian: *How come?*

Brad: Because I'm a teacher candidate walking into this school.

Brian: Okay. So you don't want to threaten your chances to get hired?

Brad: Well, and I mean there's a certain amount of, what's the word I'm looking for...politics.

Brian: Yeah?

Brad: There's a lot of politics involved.

Charlotte related during the interview the real-life consequences she may have faced if she had not spent time during her program as an advocate for herself:

Brian: What if you weren't able to advocate for yourself, what if you didn't have your agitator, advocator streak? It sounds like you don't have a problem confronting...

Charlotte: I wouldn't be in school. I wouldn't have gone to university, or maybe I would have gone and I would have dropped out after my first year.

Brian: Okay.

Charlotte: I'd be working a shitty retail job, getting paid minimum wage for the rest of my life.

Brian: Unskilled labor?

Charlotte: No room for movement because I don't have an education, cause the system wasn't accommodating.

Charlotte sees advocacy as essential to counter the inaccessibility of the "system". Like many university students, Brad and Charlotte are focused on their careers beyond their educational experiences. Both understand that advocacy during their education is important to secure gainful employment later. More than this, the two of them understand that the same advocacy needed to obtain gainful employment through a university education is in fact the advocacy used when accessing disability-related supports.

But the story with Brad and Charlotte's advocacy does not end with their sensitivity to its value in their careers. Both students understand the subtlety and strategy involved in getting access to a quality and satisfying education. Charlotte outlines her approach to getting supports from course instructors:

> I think I come off really well I have multiple approaches under my belt, the first approach I do is very gentle and very like nice and calm, my second one is like "you haven't given me shit", I don't want to say that, but I'm like "so these are the accommodations I need and this is what you are required to help me with", versus "these are what I need in order to do better". And so what I find is like I never get to the, I don't know, I think I'm too up front from the get go and I don't leave it until I have the problem, you know.

Brad encountered supervisors and instructors who felt that it might be necessary to reveal the nature of his disability to people that would not otherwise be entitled to know. Brad was successful in preventing the disclosure. Here he explains his thought process on the issue:

> I was happy that I got what I wanted, but I was also prepared to go a little further. ... I was seriously considering--if they were going to push with the [issue], I was going to mention PHIA [Public Health Information Act]. ... Plus the fact that it's a violation of PHIA, it's covered under PHIA, it's my personal health, and so I mean it's not like I kind of went in full board, yelling and screaming, pounding on the desk. ... You know that sort of thing, that's a little too far the other way. I had another professor kind of go the same route, but I spoke to her after class and she realized what, she realized that, she said "oh I hope I didn't embarrass you". And I said "well, if we could just keep that kind of stuff between you and I".

It is easy to see that Charlotte believes it easier to attract flies with honey rather than vinegar. It is also evident that Brad knows when not to play an "ace" when a "two" will do the job.

Summary

The most important feature of the theme of advocacy in this research has to do with skills gained in university in general. In addition to studying various academic disciplines, students learn verbal and written communication skills; they practice documentation and the creation of arguments that are backed up with solid evidence. They also learn the nuances of their rights and responsibilities in the context of society.

Students with disabilities are perhaps in an advantageous position when it comes to advocating for supports and the removal of barriers for themselves and others. Clearly some of them have used their university educations as a component in finding accessibility. For this reason it is reasonable to say that while a university can have disabling dimensions, it can also be an environment of enablement.

I mentioned in the last chapter that participant encounters with the university institution represented an interactive process. The specific encounters of advocacy, as described by the participants, further stress the presence of this interaction. Moreover, the advocacy encounters draw out how the disabling built environment is constructed and reconstructed by people with disabilities in social relationships with other students, faculty and administrators. These social relationships are not broad or vague, rather, they are as specific and incidental as recounted above (recall Geanette and Inez's experiences). From my point of view both compliance and resistance (and those practices in between) in the

advocacy encounter are instances where students with disabilities reconstruct the GBE of the university.

Chapter Eight: Barriers, Supports and Personal Strategies

When speaking of their postsecondary experiences, participants described a variety of barriers and supports that impacted their access to a quality and satisfying education. In their experiences of access, students often described personal strategies they used in creating their own supports or addressing barriers by themselves.

Barriers in Multiple Dimensions

Lisa described to me how writing final exams impacts her because of her disability (a medical condition involving joint inflammation):

> ...That was the worst. I hated writing [final exams] in those huge gyms. They were cold and having...once my joints get cold they just...they just cease up. And I...like I am holding a pen like this [participant displays an awkward grip on her pen] and writing. Like I am not actually holding it properly. So, cause I can't move my hands anymore. ...Yeah. An hour long I am ok with but it's the three hour exams sitting there for three hours like being confined.

> ...But in an exam situation you stretch your legs out and you're kicking the person in front of you. So it means going like this and writing for a while or turning around and going like this, the prof tends to go "what's up with you? What are you doing? What are you looking at?"

Because writing final exams is physically demanding for Lisa, she would like to set up her courses in order to space her exams out during the formal exam periods. Here she explains how this is a problem for her:

> ...There's a lot universities where right in the registration calendar they have everything laid out so that you have the choice of two different lecture sections for this course in this term or versus that in the second term because you take a look when the exams are [scheduled] and you're writing two exams in one day. Yeah, [here] you register for all of your courses like all you can do is maybe VW

[voluntarily withdrawal] or you end up having three exams in one day.

Lisa experiences barriers in both physical and temporal ways. The spacing of exam seating and use of a pencil to write a test or fill out the tiny circles on a scannable exam sheet is a problem for her. At the same time, administrative practices when it comes to the construction of calendars and exam timetables make it difficult for Lisa to make plans in advance.

Lisa's account is important because it references both physical and temporal barriers. Recall my concept of the GBE (grand built environment). The physical and temporal barriers experienced by Lisa are both "built". Also of importance in Lisa's description is how she describes the barrier of registering for courses and timing exams. Lisa is suggesting that she would like to plan her year well in advance in order to ensure her exams are well-spaced. As mentioned, this spacing is important for Lisa because of the physically intense way she experiences the testing encounter. For this participant, the removal of a barrier is not as simple as giving her well-spaced exams. Rather, she wants a different barrier removed (regarding timetabling and registration requirements) so that she can herself address the barrier of exams that are too close together during the December and April final exam periods.

Lisa is one example of a student who not only wants barriers removed, but wants to be empowered to be able to remove barriers for herself. Brad is another example. He follows on Lisa's need for empowerment rather than just blanket support in a very concise way:

...But I did it for my own, my own sake. I mean I have to advocate for myself and get the tools that I need to get the job done properly...

Larissa (32, BSc.) mentioned to me during her interview that being a mother of two was a substantial problem for her education, but that her husband plays a very large role in her support:

Larissa: I have a seven year old girl and a six year old boy.

Brian: You've got quite a handful eh?

Larissa: It's a handful. You know, I really notice it when he's [my husband] not feeling well and he can't do what he normally does or if he's working a different shift. For me, day shifts during the weekend are absolutely brutal because I can't do any work. ...And once a month he ends up having to work uh, day shift over the weekend and it's just impossible for me to do anything because I can't separate home and school. ...And my husband has been a great support. He's basically enabled me to focus solely on school and have the time that I need to put all my energy on school. If it wasn't for him, I wouldn't have been able to do it. So he's been a great support. And when I get really distracted, when I have problems focusing. When I need extra time to do things at school I am able to do it at home because he basically takes all the pressure off of me for having to be mom and wife and everything else.

Larissa's problem with the separation of home and school is not in itself disability-related. Yet she expressed to me the unusually large amount of time she needs to put into schoolwork because of her learning disability. Larissa's experience demonstrates that for some students, accessing postsecondary education has as much to do with barriers on campus as it does with barriers off campus.

Norma recalls dealing with the complex layout of a building on campus:

But um, I guess you just have to walk around trial and error. A sociology professor took me to his office, I didn't know where I was

supposed to go or where he was taking me. And uh, we went down steps and then I followed him up two flights of stairs and I just couldn't make it. And then when we got to his office I was totally lost. So when we came out of his office he says you can find your way and I am feeling ashamed now, I said yes I'll look for the red lights, the exit. Wherever I see red on the ceiling there I'll follow that I should get out somewhere. I didn't get out the way I got in anyway.

For Norma there is a dual experience. The inaccessibility and layout of the building is one problem. Dealing with this problem in the embarrassing social encounter with an instructor is the second issue. Even when an encounter with the university environment seems to be as simple as physical access, Norma's experience shows us that there is more beneath the surface. Her comfort level when it comes to disclosing her need for help (and thus her disability) ends with her going without the support she needs to leave a building the way she got in. To be sure, a person without a disability may be just as embarrassed to ask for directions, but may not be embarrassed for the same reasons.

Supports in Many Places, with Varied Results

Larissa explained that her husband is "usually" available to help with the kids. This support is not provided to her on the presupposition that it helps her address her disability. This does not mean that it has no use as a support for her in light of her disability. It is reasonable to assume that all university students parenting children would benefit from such a generic support in this regard. The value of this support may be greater still for a disabled person if the requirements of their academic program are more demanding as a result of their disability.

Larissa went on later in the interview to tell me about how the patience of her instructors went a long way to making her feel supported in her academic endeavors:

> *Larissa: And so there were a few instructors that I approached because of the concern [with my coursework]. And uh, I find in general they're really supportive. And I find faculty, it's almost like they take a little bit longer time to explain things to me. It's kind of like talking louder to make sure that they hear you. ...So, um, they're more inclined now to go over things again if I have a question. Ok, I don't understand can you tell me that again. They don't even think twice. They don't [say] ok, just go to your book and figure it out. They will take another approach at it.*
>
> *Brian: So they're happy to give you some one-on-one support there.*
>
> *Larissa: Yeah.*
>
> *Brian: And is that a value to you?*
>
> *Larissa: Yes, it is. Yeah.*

The occasional one-on-one patient support that Larissa gets from her instructors may seem like a relatively small support when compared to things like accessible exam facilities or building design. Yet Larissa finds this to be a valuable asset in her academic success.

Along with the barriers cited earlier by Lisa, she also remarked on the supports which she finds valuable at university:

> *...So having extended time to write [exams]. Being able to get up, move around, and not worry about oh shoot I only have three hours to write this, I'll have time and a half to write it. So it takes some stress off which, you know, just mentally sort of calms you down. And I can get up. I can have heating packs so that I can keep my hands warm.*

I mention this description of Lisa's supports here in order to establish that many participants cited both barriers and supports. Only one person in my participant group remarked that they experienced no barriers, and few participants expressed no positive experiences with supports.

Geanette (31, MA.) expresses great frustration with how her learning disability (LD) contributed to her prolonged program and extensive student loan:

> ...So I have eight years of student loans because of the LD. Not because I am lazy, not because I slacked off. Not because I did anything wrong. I mean there was one year in there that was really, really bad academically and that was because of the depression which was undiagnosed, with the exception of that year, I mean the reason that I have the debt load that do, is because of my learning disability. It's not because I did anything wrong. So then why is it then that I am being financially penalized for something that I had control over. ...Uh, one thing and I don't know if it's available or not, but one thing is that on your student loan form you have to fill out if you're a student with a disability. I think the definition of disability has changed so then now I would be able to check off that box.

Geanette experiences her student loan and drawn-out program as frustrating for her. She feels that these problems were the cause of her learning disability, not the cause of any actions or inactions on her part. What I would like to draw attention to here is not so much how Geanette considers her own agency, but how she considers the presence of current supports. She mentions in vague terms that student loans policies have changed to be more accommodating for students with disabilities.

There can be little doubt that supports for disabled students in postsecondary education have changed over time. Geanette's observation of this fact is interwoven with regret and frustration. Her experience shows us how

the changing (and even improving) landscape of barriers and supports over time can leave some students feeling cheated or "ripped off".

In the same way that supports for disabled students may change over time, they also may change across geographic location or educational jurisdiction. During the same interview, Geanette told me how the supports available at the U of M Disability Services allowed her academic performance to greatly improve over what it had been in a different institution:

> ...When I came to U of M my grades skyrocketed because of the accommodations. Because I wasn't able to write exams [in the same space] with everybody else. That wasn't a realistic expectation of me. Whereas once the [exam] accommodations were made I had the same expectations as other people, then I was able to succeed.

Treena (18, BA.) expressed how the presence of an accessible campus residence was a necessity for her, but that before she came to university, she was uncertain if the building would be complete:

> ...Well at the beginning when I first figured I would be moving here, the residence wasn't built yet. And so it was really, really scary knowing that it wasn't built yet because I couldn't live in the regular residences. And so without that new residence I wouldn't have been able to come.

For Treena the benefit of an accessible residence is fortunate, but not the end of the story when it comes to her experience of accessibility:

> ...Like right now I am in the process of debating whether or not I have to go talk to the director of housing because they put a fridge in my accessible room that is in that 21 million dollar brand new res and they put the freezer on top of the fridge and not the bottom. And I bang my head every single time [I use the fridge] and I pretty much have to get down on my knees to reach something. And every single one of my things is in the front of the fridge and my roommate has to put everything at the back. And a simple switch of a fridge so that's what I am in the process of it now.

Later in the interview Treena commented again on the 'brand new' building that is her residence:

>...and then you look at that brand new 21 million dollar building that they just built, they...the wheelchair ramp is a joke.

I should say at this point that Treena does not use a wheelchair or other mobility appliance. Her frustration with the accessibility problems of a supposed accessible building goes beyond her own experience to the possible experience of other people with disabilities. Treena represents an interesting instance because of this. Her personal experience of disability at university informs (and is informed by) her understanding of, and sensitivity to the barriers faced by other students with disabilities.

Keep in mind that the wheelchair ramp on the building mentioned by Treena may not in fact be a "joke" for a person who uses a wheelchair (I had no participants using wheelchairs in order to test this particular hypothesis). The specific utility and functionality of a wheelchair ramp is not my focus here. Rather, I want you to see that a disabled student is seeing the university campus in a way that highlights all barriers (conjectured or not) to access. In this manner, one student may also become an advocate for other students in spite of differences in the disability experience.

I mentioned that I did not have a participant with whom to test Treena's hypothesis about the wheelchair ramp at her residence. I did however have a participant who uses a wheelchair in other locations on campus. Jason explains

his understanding of limited accessibility when it comes to using wheelchairs in buildings:

> ...Like well when people are designing buildings they say it's going to be all state of the art and wheelchair accessible you know. And then you go in there and the first thing like I'm experiencing now because I'm in a wheelchair, certain things aren't like, like the bathroom stalls you know they're not widened or something like that.

Jason identifies the same contradiction that Treena does: even when accessibility is provided, the people for whom it is intended may still find it less than acceptable.

Jason and Treena were not the only participants to talk about available supports that were unacceptable. Inez (48, PhD) told me about the accessible parking stalls near the building where her office is located:

> ...There's a lot of handicapped parking right in front of this building. Sometimes there's six of us that need those four stalls. I can't walk any distance because of so many problems. And I can't walk holding my breath... So I have an accessibility pass, I can park out front of the building. Um, but we're having trouble getting enough space for these six people who usually need those spaces. And a couple of years ago what we were doing, a couple of us who didn't need door accessibility but in a large space, were double parking in one of the stalls. We got in shit for it, which is stupid.

It should be clear just how complicated it can be to administer and access supports at a large institution. The accessibility feature of the reserved parking stalls is provided and administered by the university. Students with disabilities (and in this case, staff) get privileged access to specific supports. When the use of the support contravenes an institutional policy, the response to the contravention can become a barrier in itself, as we see in Inez's account.

To be clear, I am not saying that supports should not be administrated over, or that misuses should not be addressed. Instead I want to draw attention to how a complicated set of accessibility procedures can become a frustrating experience for disabled students at university.

Supports in Unsuspected Places

Other students have also commented on how accessibility issues off of campus must be addressed. Serge has a seizure disorder which prevents him from holding a valid driver's license (I refer to this earlier in my discussion on gender). He told me how this was a problem and how he resolves the issue:

> **Brian:** Sure. And is the fact that you don't drive a big problem for you in terms of your education here?
>
> **Serge:** Well of course it is and it always has been a problem in terms of my life. I mean the vehicle is something that most people are quite dependent on. And uh, although, you know, like myself, I've grown used to the fact that and resigned myself the fact that I cannot drive and so I make alternate arrangements, i.e. public transportation or uh, ride my bike and walk, which is part of the exercise regime. Yeah, so I mean it's got it's pros as well as its cons but, you know, there are large inconveniences in not having a license, let alone an automobile. ...it's just the inconvenience of knowing that, you know, I can't hop in the car and drive to Safeway to get a jug of milk if I need to, so. So that's an inconvenience. And as far as getting to school, yeah, it does pose a bit of a problem but most students take the bus. So, you know, I resign myself to that too.

Serge is not so much lamenting having to use public transit as he is frustrated with the change he has experienced. He explained that his seizure problem emerged at a time in his life when he had already established routines around things like having a driver's license. It is the upset of this routine that Serge described as part of his disability experience. He adapted to this change without

any external supports. The interesting thing in Serge's account is that what is routine for many students without disabilities is in fact his adaptation to his disability.

Many students find supports for their disabilities in features of campus that are not typically considered to be disability-specific supports. One example cited by several participants was the use of private tutors. Serge talks about how his use of tutors is a support for his disability:

> ...And uh, I've received some funding and in my case it's not for special equipment because I don't need special equipment. I can see well. I am not in a wheelchair. My disability is not physical. It's neurological, so it's non-tangible. Um, what I've used the grant for was for tutoring. Uh, in my case as I say, if I am fatigued and I am not able to focus properly on what the teacher's talking about or if I lapse out into a seizure and lose track of what's going on, and I may lose the entire context of what he's talking about within the classroom. So I have to make that up somehow. And the tutoring services have helped me tremendously...

Carlo (who I mentioned earlier as having problems accessing peer support for coursework) accesses tutors to address his disability:

> *Carlo*: I get the help with the uh, tutors. Um, with that help I've been able to do most of the work.
>
> *Brian*: Right. That does help you quite a bit, eh?
>
> *Carlo*: Yes. Yes. Otherwise if I don't have that help forget it. I would never finish.

Liz also accesses tutor services as part of her disability supports:

> *Liz*: I have my tutor for like if I have psychology or art history or uh, if I have math or, you know, those type of things because I have comprehension...I forget things. I have problems organizing. I have problems editing. I forget um, like uh, when I want to um, when I want to write a paper, I can't organize my thoughts properly and it looks like a child wrote the paper....

Brian: And so how do you pay for a tutor?

Liz: Um, I get grants. I get up to $8,000 worth of grants.

The grants that Liz is referring to here are moneys administered by the Canada Student Loans program for students with disabilities. This money is non-repayable and can be used for disability-related supports.

Earlier I mentioned Larissa and the practical support she found in the form of her husband's availability with parenting. Many other students pointed to their family and friends when I asked them about what the biggest supports were for them. For example, Treena told me that her disability makes her feel very vulnerable walking across campus late at night. She explains how a friend helped her:

> *But uh, you know, I am extremely vulnerable to anything in that sort, and I would never, ever put myself in that position. Like I had a night class last term and I had a friend who would come and pick me up every single night after class.*

While Treena's walk across campus amounts to only a couple of blocks, her friend's presence was essential.

One of Inez's disabilities involves depression. She explained that this impacts her motivation, and that a community of people around her helps to give her some of her motivation back:

> *Brian: How about you? Do you get support?*
>
> *Inez: Me? Oh yeah, I've got a very good support network.*
>
> *Brian: That includes your partner, the [thesis] committee.*
>
> *Inez: My partner, my committee, my neighbors, my friends, yeah, I am doing pretty well.*

>*Brian*: Right on.

>*Inez*: But I work at it.

For Inez, the support she gets from the people around her is generalized. For Carlo, support from his classmates during an academic program in his home country was more specific:

>*Brian*: Right. When you were a student in [your home country], did you have support for disability there, or?

>*Carlo*: No, there was no support. The support I had was like I said friends and doing study groups.

Brad also talks about his family and others providing specific supports relating to his disability:

>Yeah, yeah, I mean my family helps me a lot, obviously my dad drives me around everywhere that I need to go, so, and my girlfriend too. So I mean in that way I get a lot of support there.

Sometimes the support drawn upon by participants was established many years before they came to university. Geanette explains her family and their support:

>...my parents always had undying support for me and an incredible belief that I was the most intelligent person in the world and if I wanted the sun, the moon, the stars and the skies on a silver platter I would get it because I can achieve whatever the hell I want because I am Geanette. And so there was never any question about support or love or belief.

Summary

The barriers faced by students with disabilities are varied, from absent signage for people with visual impairments to exhausting exam-writing procedures as encountered by people with disabilities that involve fatigue. The barriers are also complex—the university is an environment of many players all who have their

own responsibilities and expectations when it comes to making policy and carrying out practice. We see the complexity everywhere from accessing audio-recorded materials for a course to finding parking close to a campus building.

Supports for students with disabilities not only come in unique shapes and sizes, they also come from a wide range places, both formal and informal, on and off of campus. Something as simple as hours spent parenting or friends to encourage one to get out of bed and come to school are cited as very valuable to the academic success of the participants. Supports commonly seen as disconnected from the success of disabled people are also important (recall the tutoring used by Liz, Serge and Carlo).

As far as formal supports on campus are concerned, all participants had at some point accessed the office of Disability Services. While participants expressed a diverse set of experiences with this office, they all agreed that it was an essential part of their academic success at the University of Manitoba.

Finally, participants described several personal strategies and attributes that allowed them to address barriers to accessing their education. These strategies can be as simple and ambient as self-esteem on the one hand, and as thought-out as a daily regime of medication, sleep and exercise. Moreover, some students want to address barriers for themselves without the help of designated providers. The presence or absence of tools to do this is not always available to those students.

The fact that students want tools to create their own access (and in some cases create access where no tools exist) suggests that students with disabilities possess significant agency in the GBE and as builders of disablement or access. Recall my assertion earlier that students with disabilities help to construct the university environment. The stories of experiences with barriers and supports suggest that the interaction these students have with the university is not always effective, and is not consistent across every case. The way some disabled students observe the barriers that they themselves don't face indicates their broader consciousness of the social construction of disability.

Chapter Nine: Advice for Students with Disabilities from Students with Disabilities

The main intention of this research is to inform the creation of accessibility in the postsecondary context. Documenting student experiences of disability is only one part of arriving at sound recommendations. In my ethnographic approach, I considered the participants to be essential and invaluable experts on what is working for them and what is not when it comes to accessing their postsecondary education.

In the interview context, I asked each participant what they would like to see changed to make their university experience more accessible, and what advice they would have for other students who experience similar challenges. What follows is a series of specific advice for students with disabilities from the participants. I have purposely left out continuity in the presentation of this advice in order to emphasize the diverse experience of the participants. I have purposely left my analysis of these selections until the end in order to provide a list of advice that is less academic and more usable by the readers who are themselves students with disabilities.

Use the Services And Resources Available

> *Brian: If I could sort of say to you what advice would you have to give to other students with disabilities as they come to the U of M, would you have anything to say?*

> *Lisa: Uh, definitely don't be afraid to use the services. I was kind of hesitant to...*

> *Brian: You mean just Disability Services or other services on campus?*

Lisa: *Especially Disability Services. Yeah, well I mean specifically Disability Services because that's basically the only one I am familiar with. Um, because you're going to run into problems and especially if it's like...even again if it's an invisible disability like ADD or something or some kind of learning disability, don't feel you have to have some kind of you know, visible disability like it's just a valid disability as you know, someone who is blind or deaf. The services are there for you because you should have an equal opportunity to have an education. And if you need some extra help or if you need some extra time, you know, writing exams or tests or something like that, take it. You know, even though the prof might give you a funny look or something like that, in the end they can't...well sometimes they do...they're not supposed to mark you any different. Um, and...*

Brian: *What about personal strategies? Would you have any advice on that for students?*

Lisa: *Uh, personal strategies. Form a good--make sure you have supportive friends and if they're not supportive then they're not really your real friends. Um, make sure you have a good, supportive home environment too and if you don't you know, there's ways of getting around that too because it all comes into play when you're doing a degree especially if you've got extra needs, then it really starts to come into play, time management, any kind of thing like that.*

Brian: *What about any advice you'd have to give to other students who were just starting who have disabilities? Do you have any advice to give to them about their university?*

Carlo: *The advice I could probably give to them is look for the service as soon as you get involved, you know? Try to uh, identify yourself with uh, those services that are there for students with disabilities. And um, yeah, mainly that. So it will help, you know? If you ask a new student you don't know, like you have those things available for you. Like at the beginning I didn't know but then I said well I have this problem and then check with them. That what I started when I came here, you know, I was 100 percent sure it was going to work for me. Uh, because I was thinking maybe there's more helpful for people with other types of disabilities not just, I mean, um, people usually see people with disabilities somebody who's in a wheelchair and stuff like that, you know? So, those type of recommendations for other people, you know? Or handicapped*

people or whatever, you know. But then once I got enrolled there and I started getting the service, I was surprised.

Brian: *...what advice would you give to just any new student coming in?*

Nicola: *With a disability like mine?*

Brian: *Yeah.*

Nicola: *Lay it on the line. ...Just be straightforward.*

Brian: *To everybody? Or just to specific people?*

Nicola: *Well definitely with the Professors. I've told some, depending on if they've noticed something, and they're like what's going on. A couple of classmates, even though they don't really have the ability to hold a pen in that do, so you go from left handed to right handed to right handed in the middle of a sentence, and its kind of noticeable.*

Treena: *Probably my best advice to anybody um, like new students...anybody, anyone, those profs the reason why they come to class is because we're there and because we pay an arm and a leg to go to school and you know, they work pretty much for you and you know if they have office hours and you have a question, go.*

Be Prepared for Difficulty, But do Not Accept Defeat—Be Persistent

Brian: *What would you tell a student who was coming in, just starting fresh, who had any disability, not necessarily DID?*

Nicola: *Be prepared for hell.*

Brian: *As a disabled student, be prepared for hell.*

Nicola: *Yeah.*

Brian: *How come? What's the biggest demon?*

Nicola: *The unknown. Not knowing how people are going to react.*

Geanette: I mean the main thing I would say is don't accept defeat. Because if you failed an exam because you stayed up last night partying and you walked into the exam half three sheets to the wind, then you probably deserved to fail and that's fine. If you studied your ass off. You know you did everything right and you walked into that exam and didn't do well, then you need to advocate for yourself. Are your accommodations the best accommodations for you? Is that really the best service that you can get? Should you be getting other things? You know, is that the right class for you? Was the prof's exam fair taking into account your disability? I would...I mean the main thing I would say to any student is advocate for yourself. Take a good long look at yourself, see if your mistakes are because you're being lazy or stupid or doing something wrong, or is it because something that isn't fair, that's unjust. And if it is something that isn't fair, or unjust, then advocate for yourself, or get the support to advocate for yo8urself. And just do what you have to do, you know.

Norma: To hang in there and they're going to come up against a lot of negativity and you would be discouraged more so than the average person, but just try and be strong and hang in there. And, you know, they have a dream and aim and purpose for what they're doing, try and stick with it. And just uh, be yourself....

Brad: I would really suggest like any class I've spoken to, or I spoke to [a section of Introduction to University for students with disabilities] last September and I've also spoke at the seminars like the first day seminars at Disability Services, I've always stressed, you know, don't be afraid to ask for help first of all. Never be afraid to ask for help. And number two, if you can't get that help, don't be afraid to ask somewhere you can go to get it, and number three don't be afraid to fight to get that help.

...Yeah. And you know what, I think embrace your disability and own it.

Brian: What does that mean?

Brad: What that means to me, you just need to understand it and understand that you do have limitations and you will things that you can't do, it does not make you any less of a person or it does not belittle you as a person or a student or anything else. You just need to know workarounds too, and self pity is not really an option, for me anyways, from my perspective, I mean self pity is not a...

Brian: ...not a constructive solution.

Brad: No, exactly. Yeah that's a perfect way of putting it, because it's not really going to get you anywhere.

Brian: what would you tell somebody, sitting across from you who had a similar problem but was nineteen or twenty?

Larissa: Don't give up.

...I would advise this person not to give up. I would advise them that if you need any help come and talk to me because I've been there and I've been through it. Go talk to Student Advocacy. Don't be afraid. If you have a concern or an issue then have your voice heard. That's your right.

...You just feel so alone. You're not alone. There are people that have gone through that and there are people who can help you. There's people who are able to help not only in Disability Services but Student Advocacy. You can talk to these people and even if you just want to go to there and cry on a shoulder or grumble to them or curse and swear you know, at least you have someone who will listen to you.

Stay Dedicated to Your Studies and Know Your Limits

Brian: What about advice to other students? Like if you could sort of uh, the new students who have similar kinds of problems. Some of the kinds of disabilities that, um, what advice would you have to give them? If any?

Robert: Um, go to class. (laughs) Don't skip it. Don't drink and what not.

Brian: Would you have any advice to give to somebody who was just starting a program who had a disability? Sort of starting a program.

Serge: Well if they had a disability like my own well for that matter, because I can't judge any other kind of disabilities, like I don't know what it's like to be blind. I don't know what it's like to be in a wheelchair or, you know, so I can't...but in terms of disabilities similar to mine and I'll classify them as neurological conditions, ok?

Brian: Yeah.

Serge: Uh, my first and foremost advice would be don't take a full course load. You know, get used to it. Get a feel for it. See what you can handle because ultimately I think that if the student takes on too much, it just spells disaster, you know, it's a one way ticket to failure, I know it, I know it. And I was wise enough or fortunate enough or lucky enough to decide not to take a full course load and I think that's the only reason why I managed to get through first year ok. And uh, I made up most of those courses through spring and summer session so it really didn't make any difference in how many credits I got over the year or not much actually. I ended up getting twenty-five credit hours by the end of the year which is almost a full course load anyway. So I was satisfied with that but I had to stretch it out including spring and summer session. Well, ok, so I had to study during the summer, well c'est la vie, right? But I think that the biggest advice I would give to anyone uh, be they a mature student of someone with disabilities is don't take on too much. Get used to it. Get a feel for it and see how much you can handle before you uh, and see what the obstacles are and see how demanding it is to be dealing with before you think that you can conquer the world.

Brian: If you were sitting in front of yourself and an eighteen year old was sitting her, what advice would you give her?

Charlotte: Don't go to school.

...Being rich would be a suggestion, like win the lottery before you go to school so you can afford to buy all the shit [you need] and use it right away.

...Get a sugar daddy.

Become Familiar with Your Rights

Brian: What um, what can you tell me um, other advice you'd have for other students coming in for the first year?

Inez: With disabilities?

Brian: Yeah.

Inez: Know what your rights are.

Brian: What's the best way of finding those out?

Inez: Go to Disability Services. I literally every year in my teaching I illicit information from students about disability related issues. Yeah, you can tell me anything. If you've got a problem, I can't fix it if I don't about it

Summary

Several important features emerge when considering the advice participants offer to other students with disabilities. First, the notion of perseverance in spite of difficulty comes out loud and clear. The narratives of resilience I spoke about earlier are echoed in the advice given by participants. The message is evident— "it was tough for me, and it will be tough for you, but if I made it, then you can succeed as well". The sentiment suggests that the participants want others to see that the challenges are difficult but not impossible. For some students (Charlotte and Nicola for example), the advice given not only reflects their past difficulty, but also conveys through cynicism a feeling of discouragement. For Charlotte this cynicism is delivered with some humor ("get a sugar daddy").

The second feature that emerges about participant advice is how some of it could just as easily be offered up to other students without disabilities. From the simple yet effective strategy suggested by Robert (attend class) to more global approaches recommended by Inez (know what your rights are); the advice is not necessarily disability-specific.

The final feature I want to draw attention to here is the way participant advice reveals participant expertise. Each participant is training at university to become a professional of one kind or another. The professional skills gained in a

university program include discriminating judgment, the ability to articulate strategies in linear and coherent ways, and the ability to synthesize past lessons to come up with innovative and original thoughts. These lessons are all evident in the advice of participants and in the way which that advice is expressed.

By interacting with the GBE of the university, the participants have produced advice for other students in similar situations. They have acquired this ability for many reasons: their educations, their personal struggles, and their sensitivity to the needs of others. SMT suggests that disability is best understood in terms of how people are made disabled by their socially constructed environments. What is interesting about my participant group is that through this interaction they bring their own agency to the social construction of the GBE.

Chapter Ten: Conclusions

The outcome of this research project has been a rich documentation of the narratives of postsecondary students with disabilities at the University of Manitoba. The emphasis in the interview-based documentation is on the relationship between the disability experience and the academic experience. The value of participants' experiences and expressions to inform the creation of more accessible university environments is beyond doubt. Two specific conclusions emerge from my research and analysis.

Students as "Access-Builders"

Postsecondary students with disabilities are in and of themselves a huge resource for creating supports and removing barriers. The training afforded this participant group, and the life experience required to access the training to begin with are two important features of these people's resourcefulness. In addition, many students at university have a great deal of initiative and determination when it comes to making their programs work for them. If tools (in the form of policies and resources) are available to students, many will use them to create supports by themselves and for themselves. More than this, many students will create supports and access for others by working to do the same for themselves.

The Grand Built Environment of a university education is a complicated landscape which students must navigate in order to achieve their academic goals. This environment is social, temporal and physical. These three dimensions are socially constructed—in other words they are constructed by people in relation to each other. By this conception, an admissions requirement

is of the same ilk as a bathroom stall. Both are artificial (made by people in society and not naturally occurring) and both are encountered by people.

The place of disability in this complex multi-dimensional environment is socially constructed as well. Many players have something to say about disability, and many players define it for others. Social Model Theory emphasizes the definitions, meanings and interpretations of human biological reality as the focus of any enquiry into understanding disability. Of critical importance among these definitions and meanings is the biomedical categorization and administration of disability. It is this categorization that all disabled students must encounter in order to receive any kind of disability-specific accommodations at the University of Manitoba. Disability and the disability experience are interwoven with the socially constructed environment of a university in a way that is lived out by individual students "on the ground".

Being on the ground in the environment of a university presents multiple, complex challenges to students with disabilities. Many challenges are a combination of social, temporal and physical dimensions instead of being just physical or only temporal. Students with disabilities can feel overwhelmed as they encounter barriers that come from so many places and overlap in so many complicated ways.

Expanding the Concepts of SMT and the GBE

Students with disabilities are part of the social construction and reconstruction of the GBE of the university. At the same time that students encounter this environment, they also are part of it, and contribute to parts of its ongoing

construction at various levels. Herein lays a paradox: the complex university environment can be both overwhelming and contain barriers while simultaneously being a toolkit for students with which to create access.

When it comes to understanding how Social Model Theory works, we must consider the interactions between disabled people as social actors and the environment built by *all* social actors. Disablement through socially constructed environments of time and space is not a one-way process. As the participants' narratives suggest, the presence of agency, resistance and cooperation provide access in the same way that disablement is created—by constructing it in society.

To be sure, the process of socially constructing access is possible but not necessarily simple. The social relationships in which the construction of access/barriers occurs are influenced by the variable (and sometimes unequal) distribution of status, authority and resources. Yet, as people with disabilities acquire these advantages through university education, they become more able to assert their needs and engage in the construction of their GBE.

Michael Oliver (2004) has suggested that the Social Model of Disability is not actually a theory or a concept. He argues that too much time has been spent in the past twenty years on how the model works and where its value lies (Oliver 2004). Instead, Oliver asserts that more effort should be made to use the model in the practices of research and service provision (Oliver 2004).

To be clear, the characterization of the Social Model of Disability as a theory is not a problem for me. No theory can explain everything, and every theory can be changed when new data comes to light that is not explained by the theory as-is. Yet Oliver's advice can be heeded; SMT can be implemented in research and policy as much as it can be built on through the same process.

The Social Model emerged from the thoughts and experiences of people with disabilities, and therefore it makes sense that people with disabilities should be among those to develop the model further. My research has demonstrated that citizens (in this case, students with disabilities) are already engaged in this development whether or not they characterize it that way. Moreover, they are involved in the development of the model not through analysis and study, but through their actions as social agents.

So what does all of this mean? First, by expanding the Social Model of Disability to include actions by social agents (disabled people), we open the door to accepting things like resistance, advocacy and cooperation as part of how disability is conceived of and defined. Secondly, expansion of the model to include agency of disabled persons can help us identify the limits of this agency, and we can then focus our efforts more efficiently when we are trying to create accessible Grand Built Environments.

The Anthropology of Disability

This research fits into the landscape of previous such studies in a variety of ways. First, I have asserted that the experience of disability is one of interpersonal interaction, or inter-subjectivity. The notion of disability as a fluid

and dynamic socially constructed/reconstructed cultural feature is evident in my research. Secondly, I have explored the reality of agency in the study of disability. Students revealed themselves in my study to be social agents whose decisions and actions place them in a dynamic relationship with disability in society. Finally, my research brings anthropological notions of the "exotic other" into the light of critique and discussion. My participants were neither "heroes nor victims" (Frohlick 2005: personal communication). In my research, participant voices emerge as valuable and authoritative. At the same time, these people are not reified or deified by my study.

In short, I have studied disability with an anthropological lens. In other words, I considered the inter-subjective nature of social/cultural experience, I addressed the nature of the agency displayed by the participants, and touched on the idea of "disability-as-otherness".

This research also complements other anthropological studies of postsecondary education and disability. Like Holloway (2001) I have used the semi-structured interview to explore student experiences with the university environment. This author contributed to understanding disability and postsecondary education in the UK. I have expanded such enquiry to include Canadian experiences.

To be sure, other scholars have researched the Canadian experience of university students with disabilities. Low (1996) focused her ethnographic enquiry on the negotiation of multiple identities. I, on the other hand, have focused on student agency and how this can be applied to creating an accessible

university campus. Finally, my research gets at the lived experiences of students with disabilities as told from their point of view. Such an investigation complements more quantitative social research of Canadian students with disabilities by researchers such as Hill (1992).

By utilizing qualitative methods and involving applied dimensions, and by focusing on a Canadian University, my research complements existing investigations of disability in anthropology. In terms of broader anthropological understandings of disability and disablement, I have produced a novel contribution. Two key themes in anthropological understandings of disability include the notion of disability as "social liminality" (Murphy, 1998; Willet, 2001) and the notion of disability-as-social construction (Ingstad, 1995).

Regarding the first theme, liminality, my research suggests the presence of a social "micro-liminality". In other words, some of the participant experiences show identities in transition and how this transition relates to being disabled. Yet this liminal state of disability did not seem to significantly transcend and engulf the identities of some of the participants' lives outside of university. The micro-context of the university experience seems to carry with it (for some students) a social micro-liminality. It bears mention that the status of being a university student can easily be seen as liminal as well. When considering disability-as-liminality, my research suggests that there may be multiple liminalites that come in to play in the cultural experiences of disability.

My research provides weight the notion of disability-as-social construction. In the same way health and illness have been widely characterized by

anthropology as socially constructed, so too has disability. My research highlights aspects of personal experience that are variable and self-aware when it comes to the meaning of disability. For example, students with disabilities sometimes regard themselves as disabled only inasmuch as this provides them with access to necessary supports in the postsecondary context. As well, the narrative of disability varies so greatly across the fifteen cases in this research that disability can perhaps be considered as "personally" constructed as well as socially constructed. Finally (and as I have mentioned before), disability is revealed in my research to be not only socially constructed, but socially re-constructed by disabled people themselves.

Limits of the Study

The limits of the research are probably most evident when considering the diversity of the many specific experiences of disability, and many other social experiences such as race, class and gender. While I have highlighted how these categories of experiential diversity emerged for participants in the research, I was not able to dig very deeply into each.

The postsecondary environment in general and University of Manitoba in specific are experienced by many more people than just students with disabilities. The non-disabled student experience of postsecondary education was something I did not explore beyond more than just a cursory mention. It would be of interest to compare the experiences of students with and without disabilities at university.

Finally, the recruitment strategy employed to collect participants may have excluded some people: those people who have disabilities but do not access services on campus, those who do not frequent the spaces on campus or belong to the mailing list, and those who are disabled, but who are not as confident in their articulations and the worth of their experiences may have been left out of the research group. Because there is no formal list available, it is impossible to tell just how many potential participants were in the population.

Recommendations for Further Investigation

Although this research project has limits, it also opens up a variety of questions and suggests several avenues for future study.

- The perceptions and understandings of disability and disabled students among faculty, support staff and administration at a university.

- The experiences and careers of postsecondary students who have been working as professionals long after their university experience. How does the in-program experience compare to the in-career experience of people with disabilities?

Appendix 1: Pseudonyms and defining features of participants

Brad: 31-year-old man, single with no children, BEd program.

Carlo: 44-year-old man, married with children, BSC program.

Charlotte: 44-year-old woman, single, no children, BA program.

Geanette: 31-year-old woman, single, no children, MA program.

Inez: 48-year-old woman, married, no children, PhD program.

Jason: 19-year-old male, single, no children, BSC program.

Jennifer: 23-year-old woman, married, no children, BA program.

Larissa: 32-year-old woman, married with children, BSC program.

Lisa: 24-year-old woman, single, no children, MSC program.

Liz: 36-year-old woman, single, no children, BFA program.

Nicola: 40-year-old woman, married with children, BA program.

Norma: 71-year-old woman, married with children, BA program.

Robert: 21-year-old male, single, no children, BA program.

Serge: 44-year-old male, married with children, BEng program.

Treena: 18-year-old woman, single, no children, BA program.

Appendix 2: Form for Informed Consent

Form for *INFORMED CONSENT*

Research title:	*Facing Challenges on Campus: The Experiences of Postsecondary Students with Disabilities*
Principal Investigator (PI):	*Brian Barth* Phone:
	E-mail:

Please take your time to read this form carefully, and feel free to ask any questions.
Audio-taped and large print versions of this form are available on request.

You are being asked to participate in a research study. You qualify for participation if you are 18 years of age or older, and if you identify yourself as a person with a disability. If you voluntarily agree to participate, you will be interviewed about your experiences as a postsecondary student with a disability. The information collected will be used by the PI in the completion of a Master of Arts program in cultural anthropology at the University of Manitoba, and in the creation of other publications such as academic articles. As well, your contribution will help produce a policy recommendations report on students with disabilities at the University of Manitoba.

The interview will last about one hour, and will take place in a location that is acceptable to both you and the PI. You may be asked to attend optional follow-up interviews. If you find that the one hour interview is not long enough for you to explain your experiences, you are welcome to spend more time with the PI in that interview or in successive interviews. You will be asked to spend no more than four hours in this research project. As part of your interview, you will have the opportunity to accompany the PI on a walking tour of campus. Walking tours are optional and may not be appropriate for all participants. The walking tour is intended to help you better explain your experience with specific campus locations.

If you allow, your interview responses will be recorded as hand written notes, and/or recorded on tape. All handwritten notes and audiotapes will be kept under lock and key at the home of the PI. Only the PI and the thesis supervisor (Dr. S. Frohlick) will have access to the notes and tapes. Notes and tapes will be kept secure indefinitely by the PI for future analysis and scholarship. Your identity will remain hidden in any and all materials produced through the

scholarly analysis of the research data; pseudonyms will be used, or responses will be presented in aggregate form.

This form is only part of the process of informed consent; your continued participation should be as informed as your initial consent. You are encouraged to ask for clarification at any time. Also, at any time during your participation, you may withdraw from the study without prejudice or consequence. During the interview, you may refuse to answer any specific question(s). A copy of this consent form will be left with you for your records.

Your signature below indicates that you have read and understood the above terms of informed consent for this research study.

please check
☐ I **agree** to have my interview tape recorded.
☐ I **do not** wish to have my interview tape recorded.

☐ I **agree** to have my interview recorded in hand-written notes.
please check
☐ I **do not** wish to have my interview recorded in hand-written notes.

☐ I **agree** to be contacted for a follow-up interview (you are
please check free to refuse to participate at the time of contact).
☐ I **do not** wish to be contacted for a follow-up interview.

I wish to receive a copy of the policy recommendations report
☐ YES ☐ NO   Contact info (phone or email):

_____

_____

PARTCIPANT'S NAME (please
print)_____
PARTICIPANT'S
SIGNATURE:_____
PRINCIPAL INVESTIGATOR'S
SIGNATURE:_____
TODAY'S DATE:_____

This research is approved by the Joint Faculty Research Ethics Board of the University of Manitoba.
If you have any questions, comments or complaints about this research project, you may contact:
Margaret Bowman (JFREB Human Ethics Secretariat) at (204) 474-7122
Brian Schwimmer (Head, Department of Anthropology) at (204) 474-9361
Susan Frohlick (Thesis advisor, Department of Anthropology) at (204) 474-7872

Appendix 3: Interview Schedule

1. Can you tell me about yourself?
   a. Demographic information. (Age, gender, marital status, children, ethnicity, employment, full or part time student etc.).
   b. What are you studying at university?
2. Can you tell me about your disability?
   a. How do you experience your disability in the context of your postsecondary education?
   b. How does your disability experience in postsecondary education compare with your disability experience in your life in general?
3. Why did you decide to come to university and study _____?
   a. Did your choice have anything to do with your experiences as a person with a disability?
4. What do you plan to do once your program here is complete?
5. What sorts of things do you do outside of your life as a student (work, sports etc.)?
6. Are the various aspects of your university education accessible to you?
7. What things if any help you to better access your university education?
8. If you encounter them, what are the barriers to accessing your university education?
9. How close are these barriers related to your disability?
10. Are there any specific locations, procedures, or social contexts that create barriers for you? (For example, specific buildings; application forms; campus events; class schedules).
11. Where do you find help if you are facing barriers to your university education?
12. Do you have any personal strategies that help make your experience at university a more accessible one?
13. How would you change things to make your university education more accessible to you?
14. Do you have any advice to give other students with disabilities as they engage their university education(s)?

Appendix 4: Memorandum of Understanding

Memorandum of Understanding

To: **Janalee Morris-Wales,** Coordinator, Disability Services, University of Manitoba

CC: **Dr. Lynn Smith,** Student Advocacy/Student Resources Services, University of Manitoba

Re: Research Project: *Facing Challenges on Campus: The Experiences of Post-Secondary Students with Disabilities*

Hello,

As part of my Master of Arts program in cultural anthropology at the University of Manitoba, I am conducting thesis research that documents the experiences of postsecondary students with disabilities at the University of Manitoba. I am also employed as a lead invigilator in the office of Disability Services at the University of Manitoba. This memorandum explains how I will maintain my responsibilities as an employee of Disability Services as I carry out my research.

I will interview between 10 and 15 participants during my data collection. Participation in is voluntary, and all participants will be required to give free and informed consent (in writing) before they begin research interviews. A copy of the form for informed consent is attached. With respect to solicitation of participants, Janalee Morris-Wales has agreed to send an electronic invitation to a list of students registered with Disability Services. In addition, I will be inviting current and former U of M students with disabilities who have become known to me outside of my work with the Disability Services office.

As a lead invigilator at Disability Services, I am responsible to maintain the anonymity and confidentiality of the students who are registered with the office. Specifically, in encounters outside of my work in the office, I am to disregard the identity of students I may know through their use of Disability Services (unless said students initiate contact with me). Secondly, I must keep confidential any information I have access to through the office (regarding specific students etc.).

Because my work with Disability Services places me in contact with prospective research participants for my academic research, I must be clear: While my presence and role at the office have been advantageous in gaining acquaintance to prospective participants, I will in no way exploit this privilege in ways that compromise the confidentiality of students who use the office services. This means that, during participant solicitation, I will not use any lists or files to which I have access through my employment at the Disability Services office.

My thesis research project has been given approval by the Joint Faculty Research Ethics Board of the University of Manitoba. Please contact the Human Ethics Secretariat (M. Bowman) or myself (Brian Barth) if you have any questions.

Thank you,
Brian Barth

PH:
E-MAIL:

Appendix 5: Form for Interpreter Confidentiality

Form for *INTERPRETER CONFIDENTIALITY*

Research title: *Facing Challenges on Campus: The Experiences of Postsecondary Students with Disabilities*

Principal Investigator (PI):   *Brian Barth* Phone:
E-mail:

As an ASL interpreter for participant(s) in this research, you will have access to confidential information. All participants have been advised that their identities will be kept anonymous during this research project. All data collected will be kept confidential and secure. Your signature below indicates that you agree to maintain the anonymity of participant(s), and that you agree to keep confidential any and all information revealed during the interview process.

Interpreter's Name (please print)_____

Interpreter's Signature:_____

Principal Investigator's Signature:_____

Today's Date:_____

Appendix 6: Form for Transcriptionist Confidentiality

Form for *TRANSCRIPTIONIST CONFIDENTIALITY*

Research title: *Facing Challenges on Campus: The Experiences of Postsecondary Students with Disabilities*

Principal Investigator (PI): *Brian Barth* Phone:

                             E-mail:

As research data transcriptionist in this research, you will have access to confidential information. All participants have been advised that their identities will be kept anonymous during this research project. All data collected will be kept confidential and secure. Your signature below indicates that you agree to maintain the anonymity of participant(s), and that you agree to keep confidential any and all information revealed during the interview process.

Transcriptionist's Name (please print)_____

Transcriptionist's Signature:_____

Principal Investigator's Signature:_____
Today's Date:_____

research study

"Facing Challenges on Campus: The Experiences of Post-Secondary Students with Disabilities"

please contact me if

you are interested in

a one-hour interview.

Appendix 8: Form for Ongoing Consent

Research title: ***Facing Challenges on Campus: The Experiences of Postsecondary Students with Disabilities***

Principal Investigator (PI):   ***Brian Barth***

                      Phone:

                      E-mail:

Re: Your continued consent to participate in the research *Facing Challenges on Campus: The experience of postsecondary students with disabilities.*

Hello,

       As some of you may know, I have been hired as **Accessibility Advisor** at the office of **Disability Services** at the **University of Manitoba**. This position gives m privileged access to documents regarding student accommodations and disabilities. I am writing to inform you that your past participation in the research will in no way impact your services at the DS office. Moreover, only the information you provided in the previous interview context will be used in the research—my privileged access to student information will in no way be used for this research project.

       Finally, you have the right to withdraw your participation from this research study in light of the PI's (principle investigator's) new capacity as Accessibility Advisor. Please take the time to sign this page and check the box which indicates your continued participation or withdrawal from the research.

☐   I *agree* to continue participation in the above-named research project
(Your continued participation does not mean that you will be contacted for further interviews. Your interview data will be analyzed and included in the final research thesis and other publications. The same anonymity and confidentiality provisions still apply—refer to the earlier form for informed consent).

☐   I *do not agree* to continue participation in the above-named research project
(Your interview data will be disqualified from the research and will be destroyed).

Today's date:_____

Participant Name (*please print*):

_____

Participant Signature:_____

Appendix 9: Recruitment Invitation

Hello,

You are invited to participate in a research study on students with disabilities at the University of Manitoba (titled "Facing Challenges on Campus: The Experiences of Post-Secondary Students with Disabilities"). You are eligible to participate if you are 18 years of age older, and if you identify yourself as a person with a disability.

If you agree to participate, you will be asked for a one hour interview about your experiences as a university student with a disability. If you require, large print or audio-taped versions of all text materials can be provided. As well, if you require an ASL interpreter, one will be provided. Interviews will be conducted at a location and time that is comfortable for both you and the researcher.

Please contact me if you are interested.

Brian Barth
email:
Phone

References Cited and Selected Bibliography

Abberley, P. 1987 The Concept of Oppression and the Development of a Social Theory of Disability. Disability, Handicap and Society 2(1):5-19.

ALbrecth, G. L., Katherine D. Seelman, and Michael Bury 2001 Handbook of Disability Studies. Thousand Oaks, CA.: Sage Publications Ltd.

Altman, Barbara M.2004 Disability Definitions, Models, Classification Schemes, and Applications. *In* **Handbook of Disability Studies**. G. L. ALbrecth, Katherine D. Seelman, and Michael Bury, eds. Thousand Oaks, CA.: Sage Publications Ltd.

Armstrong, Felicity and Len Barton 1999 Disabiltiy, Human Rights and Education: Cross-cultural Perspectives.London: Open Univeristy Press.

Babbie, Earl 1995 The Practice of Social Research.Balmont: Wadsworth Publishing Co.

Barnes, Colin1996 Theories of Disability and the Origins of the Oppression of Disabled People. *In* Disability and Society: Emerging Issues and Insights. L Barton, ed. Pp. 43-60. Essex: Addison Wesley Longman Ltd.

Barnes, Colin and Geof Mercer 2004 Implementing The Social Model of Disability: Theory And Research. Leeds: The Disability Press.

Barrett, Stanley R. 1998 Anthropology: A Student's Guide to Theory and Method.Toronto: University of Toronto Press.

Beckstead, Desmond and Vinodrai, Tara. Dimensions of Occupational Changes in Canada's Knowledge Economy, 1971-1996. 2003. Ottowa, Statistics Canada.
Ref Type: Report

Bernard, H. R. 1995 Research Methods in Anthropology: Qualitative and Quantitative Approaches.Walnut Creek: AltaMira Press.

Blaxter, Mildred 1976 The Meaning of Disability.London: Heinmann Educational Books Ltd.

Boylan, Esther 1991 Women and Disability. London: Zed Books Ltd.

Bryman, Alan 2001 Social Research Methods. Oxford: Oxford University Press.

Butler, Ruth and Hester Parr 1999 Mind and Body Spaces: Geographies of Illness, Impairment and Disability. London: Routledge.

Charlton, James I. 1998 Nothing About Us Without Us: Disability Oppression and Empowerment. Berkeley: University of California Press.

Chouinard, Vera and V. A. Crooks 2003 Challenging Geographies of Ableness: Celebrating How far We've Come and What's Left to be Done. The Canadian Geographer 47(4):383-385.

Colligan, Sumi 2001 The Ethnographer's Body as Text and Context: Revisiting and Revisioning the Body Through Anthropology and Disability Studies. Disability Studies Quarterly 21(3):113-124.

Creswell, John W. 1998 Qualitative Inquiry and Research Design: Choosing Among Five Traditions. Thousand Oaks: Sage Publications Ltd.

Creswell, John W. 2003 Research Design: Qualitative, Quantitative, and Mixed Methods Approaches. Second edition. Thousand Oaks, CA.: Sage Publications Ltd.

Davies, Charlotte A. 1999 Reflexive Ethnography: A Guide to Researching Selves and Others\.London: Routledge.

Davis, Lennard J. 1997 The Disability Studies Reader. New York: Routledge.

Dejong, G 1994 Toward a Rresearch and Training Capacity in Disability Policy. Policy Studies Journal 22(1):152-60.

DeJong, Gerben 1979 Independent Living: From Social Movement to Analytic Paradigm. Arch Phys Med Rehabil 60435-446.

Drake, R. F.2001 Welfare States and Disabled People. In Handbook of Disability Studies. G. L. ALbrecth, Katherine D. Seelman, and Michael Bury, eds. Thousand Oaks, CA: Sage Publications Ltd.

Driedger, Diane 1989 The Last Civil Rights Movement: Disabled Peoples' International. London: C. Hurst and Co.

Duquette, Cheryl 2000 Experiences at University: Perceptions of students with disabilities. The Canadian Journal of Higher Education 30(2):123-142.

Enns, Henry1989 The Historical Development of Attitudes Toward the Handicapped: A Framework for Change. *In* Treating Families With Special Needs. D. S. Freeman and B. Trute, eds. Pp. 175-186. Ottowa: Alberta Association of Social Workers.

Enns, Henry, Olga Krassioukova, and Jim Derksen2004 The Impact of Globalization on Persons With Disabilities. *In* Globalization and Community: Canadian Perspectives. J.-L. Chodkiewicz and Raymond E. Wiest, eds. Pp. 171-178. Winnipeg: Department of Anthropology, University of Manitoba.

Ervin, Alexander M. 2000 Applied Anthropology: Tools and Perspectives for Contemporary Practice. Needham Heights: Allyn and Bacon.

Evans, G.2001 Pursuing Postsecondary Education Opportunities for Individuals With Disabilities. *In* Life Beyond the Classroom: Strategies for Young People With Disabilities. Paul Wehemen, ed. Baltimore, MA.: Paul H. Brooks Publishing Co.

Fawcett, Gail 1996 Living with Disability in Canada: An Economic Portrait. Ottowa: Human Resources Development Canada, Office for Disability Issues.

Ficten, C. S. 1995 Success in Postsecondary Education: Hidden Barriers. Rehabilitation Digest 16(21):16-21.

Finklestein, Victor 1980 Attitudes and Disabled People. Geneva: World Health Organization.

Finlay, Linda and Brendan Gough 2003 Reflexivity: A Practical Guide for Researchers in Health and Social Sciences. Oxford: Blackewell Science Ltd.

Finlon-Dajani, Karen 2001 What's in a Name? Terms Used to Refer to People With Disabilities. Disability Studies Quarterly 21(3):196-209.

Glaser, Barney G. 1992 Basics of Grounded Theory Analysis. Mill Valley, CA: Sociology Press.

Hales, Gerald 1996 Beyond Disability: Towards an Enablling Society.London: Sage Publications Ltd.

Hertz, Rosanna ed. 1997 Reflexivity and Voice. Thousand Oaks, CA.: Sage Publications Inc.

Hill, J. L. 1992 Accessibility Students With Disabilities in Universities in Canada. Canadian Jounal of Higher Education 2248-83.

Holloway, Sarah 2001 The Experience of Higher Education From the Perspective of Disabled Students. Disability and Society 16(4):597-615.

Hubka, D and Kilian, E. Employment Opportunities for Postsecondary Students With Disabilities. 1996. Ottawa, National Education Association of Disabled Students.
Ref Type: Report

Hughes, B. and K. Paterson 1997 The Social Model of Disability and the Disappearing Body: Towards a Sociology of Impairment. Disability and Society 12(3):325-340.

Human Resources Development Canada. The School to Work Transition of Postsecondary Graduates in Canada. 1-35. 2001. Ottawa, Human Resources Development Canada.
Ref Type: Report

Human Resources Development Canada. Defining Disability: A Complex Issue. 2003. Ottawa, Office for Disability Issues, Human Resources Development Canada.
Ref Type: Report

Ingstad, Beatrice and Susan R. Whyte 1995 Disability and Culture. Berkeley: University of California Press.

Janus, Raizi A. 1999 Mapping Careers with LD and ADD Clients: Guidebook and Case Studies. New York: Columbia University Press.

Jenkins, Richard 1991 Disability and Social Stratification. The British Journal of Sociology 42(4):557-580.

Johnstone, David 2001 An Introduction to Disability Studies.2 edition.London: David Fulton Publishers Ltd.

Jones, Margaret, John Siraj-Blatchford, and Kate Ashcroft 1997 Researching Into Student Learning and Support In Colleges and Universities.London: Kogan Page Ltd.

Kasnitz, Devva, Mary Switzer Fellow, and Russell P. Shuttleworth 2001 Introduction: Anthropology in Disability Studies. Disability Studies Quarterly 21(3):2-17.

Kilian, E. and Hubka, D. Working Towards a Coordinated National Approach to Services: Accommodations and Policies for Postsecondary Students With Disabilities. 1999. Ottowa, National Education Association of Disabled Students.
Ref Type: Report

Kittay, Eva, Anita Silvers, and Susan Wendel 2002 Feminism and Disability. Hypatia: Hypatia.

Knox, Paul L. 1987 The Social Production of The Built Environment. Progress in Human Geography 11354-376.

Lavallee, L. B., I. S. Pereboom, and T. Wannell 2000 Employment Equity Groups Among Postsecondary Graduates. Hull, PQ: Human Resources Development Canada.

Laws, Glenda 1994 Oppression, Knowledge and The Built Environment. Political Geography 13(1):7-32.

Low, Jaqueline 1996 Negotiating Identities, Negotiating Environments: An Interpretation of The Experiences of Students With Disabilities. Disability and Society 11(2):235-248.

Lupton, Deborah 1997 The Imperative of Health: Public Health and The Regulated Body. London: Sage Publications Ltd.

Manitoba Family Services and Housing. Full Citizenship: A Manitoba Provincial Strategy on Disability. 2001. Winnipeg, Manitoba Family Services and Housing.
Ref Type: Report

Marks, Deborah 1999 Disability: Controversial Debates and Psychological Perspectives. London: Routledge.

Morris, J 1996 Encounters With Strangers: Feminism and Disability.London: Women's Press.

Morris, Janalee 2000 Working for Equity: Issues of Employment for Youth WIth Disabilities. Master of Arts dissertation, Thesis, University of Manitoba.

Murphy, Robert, J. Scheer, Y Murphy, and R. Mack 1988 Physical Disability and Social Liminality: A Study in the Rituals of Adversity. Social Science and Medicine 26235-242.

Nagler, Mark 1993 Perspectives on Disability.Hamilton: Health Markets Research.

NEADS (National Education Association of Disabled Students. Transition From School to Work: Career Choices for Youth With Disabilities. 1997. Ottowa, NEADS (National Education Association of Disabled Students.
Ref Type: Report

Oliver, Michael 1983 Social Work with Disabled People.Basingstoke: Macmillan.

Oliver, Michael 1990 The Politics of Disablement.London: MacMillan Education Ltd.

Oliver, Michael 1991 Social Work: Disabled People and Disabling Environments. London: Jessica Kingsly Publishers.

Oliver, Michael1996 A Sociolgy of Disability of a Disablist Society? *In* Disability and Society: Emerging Issues and Insights. L Barton, ed. Pp. 18-42. Essex: Wesley Longman Ltd.

Peace, William J. 2001 The Artful Stigma. Disability Studies Quarterly 21(3):125-137.

Roulstone, Alan 1998 Enabling Technology: Disabled People, Work, and New Technology. Buckingham: Open University Press.

Sage, Francis K. and Kathleen Manning 2003 Research in The College Context: Approaches and Methods.New York: Brunner-Routledge.

Statistics Canada. Adults With Disabilities: Their Employment Education
Characteristics. 1993. Ottawa, Statistics Canada.
Ref Type: Report

Statistics Canada: Housing, Family and Social Statistics Division. A Profile of
Disability in Canada. 2002. Ottawa, Canadian Minister of Industry.
Ref Type: Report

Statistics Canada: Housing, Family and Social Statistics Division. Disability
Supports in Canada 2001. 2003. Ottawa, Canadian Minister of
Industry.
Ref Type: Report

Statistics Canada: Housing, Family and Social Statistics Division. Education,
Employment and Income of Adults With and Without Disabilities -
Tables. 2003. Ottawa, Canadian Minister of Industry.
Ref Type: Report

Stone, Emma and Mark Priestley 1996 Parasites, Pawns and Partners: Disability
Research and the Role of Non-Disabled Researchers. The British
Journal of Sociology 47(4):699-716.

Taylor, Steven J. and Robert Bogdan 1984 Introduction to Qualitative Research
Methods: The Search for Menings. New York: John Wiley and Sons.

The Society for Disability Studies. Guidelines for Disability Studies. Society for
Disability Studies. 2004.
Ref Type: Data File

The Swedish Council for Building Research. The Built Environment and the
Handicapped: Towards a Normal Life for the Disabled and the
Elderly. 1981. Gothenburg, Sweden.
Ref Type: Conference Proceeding

Thomas, C. and M. Corker2002 A Journey Around The Social Model. *In*
Disability/Postmodernity: Embodying Disability Theory. M. Corker
and T. Shakespeare, eds. London: Continuum.

Tichkosky, Tanya 2001 Disability: A Rose By Any Other Name" "People-First"
Language in Canadian Society. Canadian Review of Sociology and
Anthropology 38(2):125-140.

Tregaskis, Claire 2002 Social Model Theory: The Story So Far. Disability and
    Society 17(4):457-470.

Union of the Physically Disabled Against Segregation. Fundamental Principles of
    Disability. 1976. London, UPIAS.
    Ref Type: Report

University of Manitoba Office of Institutional Analysis. Undergraduate Enrolment
    Regular Session 1997-2002. 2004. Winnipeg, MB, University of
    Manitoba.
    Ref Type: Data File

Wannell, T. and Caron, N. A Look at Employment-Equity Groups Among Recent
    Postsecondary Graduates: Visible Minorities, Aboriginal Peoples and
    The Activity Limited. 1994. Ottawa, Statistics Canada.
    Ref Type: Report

Wehemen, Paul 2001 Life Beyond The Classroom: Transition Strategies for
    Young People with Disabilities. Baltimore: Paul H. Brooks Publishing
    Co.

Wendell, S. 1996 The Rejected Body: Feminist Philosophical Reflections on
    Disability. New York: Routledge.

Wendell, Susan 1997 Toward a Feminist Theory of Disability. *In* The Disabilty
    Studies Reader. Lennard J. Davis, ed. Pp. 260-278. London:
    Routledge.

Willet, Jeffrey and Mary J. Deegan 2001 Liminality and Disability. Disability
    Studies Quarterly 21(3):137-152.

World Health Organization. International Classification of Functioning, Disability
    and Health. World Health Organization . 2004.
    Ref Type: Electronic Citation

Yin, Robert K. 2003 Case Study Research: Design and Methods. Third edition.
    Thousand Oaks, CA.: Sage Publications Inc.